

FACTORS INFLUENCING PARTICIPATION OUTCOMES OF YOUNG ADULTS WITH AUTISM SPECTRUM DISORDER

Anne Veronica Kirby

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Approved by:

Grace Baranek

Nancy Bagatell

Brian Boyd

Mark Klinger

Gael Orsmond

Wanqing Zhang

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ABSTRACT

Anne Veronica Kirby: Factors Influencing Participation Outcomes of Young Adults with Autism Spectrum Disorder
(Under the direction of Grace Baranek)

Individuals with autism spectrum disorder (ASD) are consistently described in extant literature to struggle with crucial aspects of adult participation—specifically, participation in employment, daily living independence, and social relationships. The purpose of this project was to enhance understanding of factors that influence these outcomes for young adults with ASD. Three specific aims were addressed, each with a distinct methodological approach. First, a systematic review of the literature was conducted to identify key longitudinal factors that predicted participation outcomes; twelve publications—reporting on eight unique studies—were included. Significant longitudinal predictors of outcomes resulting from the review included personal characteristics, individual functioning (e.g., cognition, language skills, independence), family context (e.g., household income, parent education, family support), services, peer influence, and health status. Next, secondary data from a national, longitudinal sample of youth with ASD (the National Longitudinal Transition Study-2; NLTS2) were utilized to test a structural equation model which revealed parent expectations as a significant mediator of the paths from family background and functional performance to young adult participation outcomes; significant indirect paths were identified from family background, functional performance, and gender to outcomes. Finally, qualitative interviews were conducted with seven mothers of adolescent males with ASD to explore factors that contribute to the development of

their expectations for their sons' futures. Three themes were identified which describe influences on mothers' expectations: (1) characteristics and experiences of youth; (2) maternal perceptions, beliefs, and emotions; and (3) stereotypes, stories, and society. The mothers also described the approaches they use to plan and prepare their sons for adulthood. These approaches were reflective of their expectations which helps explain why parent expectations predict to young adult outcomes. Findings across the three aims led to identification of key factors that influence the outcomes of young adults with ASD as well as understanding of complex interconnections and relationships among factors. The results build upon existing empirical and theoretical work related to the transition to adulthood for individuals with ASD and contribute novel insights relevant for future research and clinical practice.

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LIST OF ABBREVIATIONS AND SYMBOLS

ADI	Autism Diagnostic Interview
ADOS	Autism Diagnostic Observation Schedule
APA	American Psychiatric Association
ASD	Autism spectrum disorder
β	Standardized beta statistic
B	Unstandardized beta statistic
CARS	Childhood Autism Rating Scale
CDC	Centers for Disease Control
CFI	Comparative Fit Index
CI	Confidence interval
E-V	Expectancy-Value (theory)
FB	Family background
FP	Functional performance
IACC	Interagency Autism Coordinating Committee
ID	Intellectual disability
IDEA	Individuals with Disabilities Education Act
IES	Institute for Education Sciences
IQ	Intelligence quotient
M	Mean
n	Sample size
NCWD	National Collaborative on Workforce and Disability
NLD	Nonverbal learning disorder

NLTS2	National Longitudinal Transition Study-2
nr	Not reported
Out	Young adult outcome
p	p-value
PE	Parent expectations
PIQ	Performance intelligence quotient
PPVT	Peabody Picture Vocabulary Test
RMSEA	Root Mean Square Error of Approximation
SD	Standard deviation
SE	Standard error
SRS	Social Responsiveness Scale
TLI	Tucker Lewis Index
VABS	Vineland Adaptive Behavior Scales
WLSMV	Weighted least squares estimator (diagonal weight matrix)
χ^2	Chi-square statistic

CHAPTER 1: BACKGROUND AND LITERATURE REVIEW

1.1 Introduction

Young adults with autism spectrum disorder (ASD) are continually reported to struggle with regard to critical aspects of adult life—specifically, participation in employment, daily living independence, and social relationships. The current project explored factors that contribute to these participation outcomes by addressing three primary aims:

Aim 1. Identify—from existing literature—key longitudinal factors influencing participation outcomes within and across three domains (i.e., employment, daily living independence, and social relationships) for adults with ASD (See Chapter 3).

Aim 2. Determine the extent to which caregiver expectations mediate the relationship between factors related to youth (e.g., level of independence) and family background (e.g., socioeconomic status), and participation outcomes for young adults with ASD (See Chapter 4).

Aim 3. Investigate how caregivers develop expectations for the future adult participation of their adolescent children with ASD (See Chapter 5).

The aims were addressed using different methodological approaches and each is detailed in a single manuscript-style chapter (Chapters 3-5). To lay the groundwork for the project as a whole, this chapter provides a general overview of the diagnosis of ASD and reviews extant literature on participation among youth and adults with ASD.

1.2 Autism Spectrum Disorder

ASD is a behavioral diagnosis given to individuals with marked impairments in social communication and social interaction paired with restricted and repetitive behaviors that impact daily functioning (APA, 2013). The diagnosis is more common among males than females—with a reported ratio of 4.5 to 1 (CDC, 2014)—but is identified across people of different backgrounds including race, ethnicity, and socioeconomic status (Blumberg et al., 2013; CDC, 2014; IACC, 2011). Though it has been historically thought of as a childhood disorder, symptoms and functional impairments persist throughout the lifespan in the vast majority of cases (Howlin, Goode, Hutton, & Rutter, 2004; Farley et al., 2009; Levy & Perry, 2011; Seltzer et al., 2004; Taylor & Seltzer, 2010; see Fein et al., 2013 for an exception).

ASD first came to public awareness in the 1940s with Leo Kanner's (1943) clinical case descriptions of 11 children with autism (Baker, 2013). Since then, there has been a consistent rise in the reported prevalence of ASD (Blumberg et al., 2013; CDC, 2014). The most current monitoring report indicates that an estimated 1 in 68 eight-year-old children in the United States (U.S.) have ASD, representing a 123% increase from 2002 to 2010 (CDC, 2014). Although most heavily monitored in the U.S., evidence suggests that the rising prevalence is consistent across nations and cultures (e.g., United Kingdom: Baron-Cohen et al., 2009; South Korea: Kim et al., 2011). It is debatable whether the worldwide increases are a reflection of improved awareness and access to services or a true increase in prevalence (Blumberg et al., 2013; CDC, 2012; Shattuck, 2006). However, based on the available evidence, it seems likely that a combination of factors contribute to the increases in reported numbers of individuals with ASD.

As implied with its label as a spectrum disorder, there is marked heterogeneity in the diagnosis of ASD (IACC, 2011). Specifically, there exists substantial variability in the range

and severity of symptoms which can complicate how we understand causal factors (Betancur, 2011; Georgiades, Szatmari, & Boyle, 2013), associations with functional behavior (Levy & Perry, 2011), and trajectories (Seltzer et al., 2004). Furthering the challenges experienced in the lives of people with ASD, many individuals have co-occurring conditions (IACC, 2011) including intellectual disability (CDC, 2014), language disorders (Bishop, 2010), learning and attentional disorders (Rommelse, Franke, Geurts, Hartman, & Buitelaar, 2010), medical diagnoses (Bauman, 2010), and psychiatric diagnoses (e.g., anxiety and depression; Ghaziuddin Ghaziuddin, & Greden, 2002; Kim, Szatmari, Bryson, Streiner, & Wilson 2000; Simonoff et al., 2008). Additionally, it is clear that there is not a single cause of ASD; rather, it seems to be related to myriad combinations of genetic and environmental factors (Betancur, 2011; Daniels, 2006; DiCicco-Bloom et al., 2006). With such variation in the presentation of the disorder, research aimed at developing comprehensive knowledge about the life course of people with ASD is needed in order to develop interventions and supports to improve well-being.

The core features of the diagnosis present in varying patterns among individuals with ASD, thus creating diversity in the manner and extent of impact on activities in daily life. Social impairments can include failure to initiate or carry on conversation, atypical social behavior (e.g., inappropriate eye contact or body language), and difficulty maintaining and understanding relationships with others (APA, 2013). Restricted and repetitive behaviors seen in people with ASD can include repetitious motor movements, inflexible adherence to routines, ritualized behavior, or unusual interactions with sensory input (APA, 2013). In childhood, these behaviors can influence the extent to which an individual can form social relationships (Dawson, Hill, Spencer, Galpert, & Watson, 1990; Mazurek & Kanne, 2010), engage in social learning opportunities with their family and peers (Kaminsky & Dewey, 2001; Vivanti & Rogers, 2011),

and participate in school and play (Eaves & Ho, 1997; Rotheram-Fuller, Kasari, Chamberlain, & Locke, 2010; Williams, Reddy, & Costall, 2001). In adulthood, challenges can be seen in the extent to which an individual can participate in employment, daily living, and social activities (Levy & Perry, 2011; Mazurek, 2013; Seltzer et al., 2003; Shattuck et al., 2007). However, there is substantial variability in the daily functioning and quality of life of individuals and their families.

1.3 Participation of Youth and Adults with ASD

The term ‘participation’ is defined by the World Health Organization (WHO) in the International Classification of Functioning, Disability, and Health (ICF; WHO, 2001) as involvement in all areas of life which is considered to relate to one’s functioning as a member of society. To understand the participation of individuals with ASD and their families, I draw from literature within occupational science and from the interdisciplinary autism scholarship. The discipline of occupational science focuses on participation in life activities (i.e., occupations) with an inherent assumption that participation in occupations influences health, well-being, and the essence of human experience (Clark et al., 1991; Law, Steinwender, & Leclair, 1998; Wilcock, 1999; Yerxa, 1993; Yerxa et al., 1990). Within the occupational science literature, there is an emphasis on the meaning and value of participation for individuals with ASD, as well as factors that produce challenges to healthy and meaningful participation for individuals and their families. Drawing from an occupational science perspective, I assert that the manner with which people with ASD participate in activities, the meaning of their activities, their struggles and successes, and their intentions for future participation contribute to their quality of life, wellbeing, and overall health (Law et al., 1998; Vessby & Kjellberg, 2010). In this project, I explored factors contributing to the participation outcomes of young adults with ASD to address

the overall goal of discovering more about mutable factors and avenues that can be used to support successful participation and ultimately improved quality of life in adulthood.

Previous work within occupational science has identified ways in which families of children with ASD experience daily struggles related to participation. For example, Larson (2006) identified that family activities and routines are seen by families as necessary, but can be challenging due to diagnostic features such as sensory-related behaviors (Bagby, Dickie, & Baranek, 2012; Marquenie, Rodger, Mangohig, & Cronin, 2011; Schaaf, Toth-Cohen, Johnson, Outten, & Benevides, 2011). Larson (2006) also found that the families in her study felt their child was often a “wildcard,” making meaningful participation in family activities stressful. In fact, some families may feel that autism becomes their family identity (DeGrace, 2004), driving the way that families participate in activities (Marquenie et al., 2011). Interestingly, Bagatell, Cram, Alvarez, and Loehle (2014) found that although the frequency of routines did not differ between families of adolescents with ASD and those with typical development, that the quality was distinctly different. Most notably, occupational science research suggests that the positive meaning typically associated with participation in activities as a family is reduced in families of children with ASD (DeGrace, 2004; Marquenie et al., 2011).

Additional research from occupational science suggests that the ways in which individuals with ASD participate in activities may contribute to how they view themselves (i.e., their identity; Bagatell, 2007; Haertl et al., 2013; Spitzer, 2003). The types of activities individuals engage in, the ways that they engage, and the meaning associated with their participation are strongly tied to their feelings about themselves. Additionally, engaging in activities with others can contribute to the development of relationships and a sense of community (Bagatell, 2010). Most of this literature suggests that identity development and

management is challenging for individuals with ASD. This type of identity exploration and development is often considered to occur most substantially during adolescence and young adulthood (Repetti et al., 2011; Reyna et al., 2012). Therefore, the connection between participation and identity development provides additional support for the importance of exploring participation during the period of emerging adulthood, which is the focus of this dissertation.

Emerging adulthood. Adolescence and young adulthood span a period of immense social, emotional, cognitive, neurological, and physical development (Repetti et al., 2011; Reyna et al., 2012). During this period, the groundwork for the rest of one's life is often laid through the development of skills, habits, and knowledge that will inform future productivity and health (Reyna et al., 2012). New personal interests are often explored and identities are shaped as youth begin to make decisions about their future (Repetti et al., 2011). Contemporaneously, as changes are occurring within individuals, their contexts and situational demands are also changing. Subotnik (2009) described that, "Standards, rules, and stakes change during the transition from adolescence into adulthood" (p. 158).

"Emerging adulthood" was a term coined by Arnett (1994, 1997, 2000) to describe the time between when the transition to adulthood has begun and the time at which one considers him or herself to be an adult, with an implication that this period is individually and subjectively defined (Arnett, 1994). Literature suggests that the subjective experience of becoming an adult importantly involves making decisions about one's own beliefs and values, accepting responsibility for one's actions, and establishing an equal relationship with one's parents (Arnett, 1994, 1997). Whereas objective measures of adult success usually involve data about whether or not youth attained specific goals including graduating from college, entering a stable career path,

marrying, and becoming a parent (Hogan & Astone, 1986; Repetti et al., 2011). The transition to adulthood in the literature on individuals with disabilities—including ASD—primarily focuses on more objective role-based and domain-specific aspects of adulthood as measures of success (Taylor, 2009).

Because the extant literature has emphasized their importance for young adults with ASD, the current project focused on three domains of participation outcomes in young adulthood: employment, daily living independence, and social relationships. These three areas—often measured in terms of work status, residential situation, and number or quality of friendships—have been considered by a number of studies as indicators of ‘overall’ or ‘social’ outcome (Farley et al., 2009; Howlin et al., 2004; Howlin, Moss, Savage, & Rutter, 2013); I refer to them throughout this dissertation as *participation outcomes* or, more generally, as *outcomes*. There is an emphasis on the importance of these three areas of participation in the available literature, thus allowing this dissertation to contribute directly to the extant literature. Similar classifications have also been suggested as primary domains of participation in the occupational therapy literature (e.g., Kielhofner, 2002).

Until recently, the expansive literature in the field of autism has largely focused on childhood (Levy & Perry, 2011; Taylor, 2009; Seltzer et al., 2004). Research on adolescents and adults with ASD has only recently begun gaining traction in the past two decades (Levy & Perry, 2011). The cause of this may be that ASD is a relatively new diagnosis; it was first described by Kanner in the 1940s and, thus, the diagnosis is only about 70 years old (Baker, 2013; Levy & Perry, 2011). This means that the children who were first identified by Kanner—those that are still alive—are in older adulthood now. Therefore, the research on transitioning to adulthood and adult outcomes has only recently become possible.

Outcomes in adulthood. Understanding adult outcomes common for individuals with ASD helps to inform intervention, planning, and supports. The literature on adults with ASD has primarily used descriptive approaches. Some studies have tracked child cohorts into adulthood (e.g., Billstedt, Gillberg, & Gillberg, 2011; Eaves & Ho, 2008; Farley et al., 2009; Howlin et al., 2013) and others have used comparison groups of individuals with other diagnoses to help describe this population (e.g., Cadman et al., 2012; Shattuck, Orsmond, Wagner, & Cooper, 2011; Shattuck et al., 2012; Shogren & Plotner, 2012). Many studies have taken a cross-sectional approach to describe adults with ASD, but some large, longitudinal research has focused on adolescence and adulthood. For example, the National Longitudinal Transition Study-2 (NLTS2) studied high school students receiving special education services throughout the U.S and tracked participants as they transitioned out of school and into adulthood. Much of the ASD-related literature on adolescents, young adults, and transition has come out of this study (e.g., Carter, Austin, & Trainor, 2012; Liptak, Kennedy, & Dosa, 2011; Shattuck et al., 2011; Shattuck et al., 2012; Shogren & Plotner, 2012). Other studies have been based in U.S. (e.g., Cimera & Cowan, 2009; Farley et al., 2009; Lounds et al., 2007; Orsmond et al., 2004; Taylor & Seltzer, 2011) as well as the United Kingdom (Cadman et al., 2012; Howlin et al., 2013), Canada (Eaves & Ho, 2008), and Sweden (Billstedt et al., 2011). This body of descriptive research has explored foci such as general outcomes (Eaves & Ho, 2008; Farley et al., 2009; Howlin et al., 2013), quality of life (Billstedt et al., 2011), employment (Carter et al., 2012; Cimera & Cowan, 2009; Holwerda et al., 2012; Shattuck et al., 2012; Taylor & Seltzer, 2011), education (Shattuck et al., 2012; Taylor & Seltzer, 2011), social participation (Liptak et al., 2011; Orsmond, Krauss, & Seltzer, 2004; Shattuck et al., 2011), and impact on caregivers (Cadman et al., 2012; Lounds et al., 2007; Orsmond, Seltzer, Greenberg, & Krauss, 2006).

One of the most heavily studied variables in this body of literature is employment outcome. The results are variable—and many studies used varying data collection methods—however, many of the studies point to poor participation in employment for adults with ASD (Hendricks & Wehman, 2009). Studies suggest that individuals with ASD have low rates of employment (e.g., Carter et al., 2012; Holwerda et al., 2012; Shattuck et al., 2012). They are also reported to work in segregated settings (Carter et al., 2012), at menial jobs (Taylor & Seltzer, 2011), switch jobs frequently (Hendricks & Wehman, 2009), and have low wages and hours (Taylor & Seltzer, 2011), even when compared to individuals with other disabilities (Cimera & Cowan, 2009). Shattuck et al. (2012) suggested that individuals with ASD may be at risk for a period of struggle in this domain after high school, especially in the first two years after transition. However, in a longer-term follow-up study, Howlin et al. (2013) suggested that struggles for adults with ASD may persist long-term.

Educational outcomes have also been explored for this population. Rates of graduation with a diploma are reported to be low, with many students in the U.S. merely “aging out” of the system (Hendricks & Wehman, 2009). Despite the wide range of IQ levels seen among individuals with ASD, participation in postsecondary education is also relatively low (Eaves & Ho, 2008). Holwerda et al. (2012) identified that there is an ambiguous association between education and employment in that more education is not necessarily beneficial for work outcomes for young people with ASD. Shogren & Plotner (2012) also determined that students with ASD rarely took an active role in the high school transition planning process and made less progress on transition goals than comparison groups.

The social relationship outcomes reported across studies point to poor social integration among young people with ASD. A number of studies have reported that the majority of the

individuals they studied were described to have no friendships (e.g., Billstedt et al., 2011; Liptak et al., 2011) and to be socially isolated (Liptak et al., 2011). Their participation in social activities with peers is typically limited, especially regarding group activities (Shattuck et al., 2011). However, NLTS2 participants who did participate in group activities typically did so within groups of people with disabilities (Shattuck et al., 2011). Underscoring the importance of studying the social participation of youth with ASD, Billstedt et al. (2011) suggested that participation in recreational activities was associated with increased quality of life for this population.

There are also impacts on the families of individuals with ASD beyond childhood. Many studies have determined that the majority of young adults with ASD live with their parents (e.g., Farley et al., 2009; Taylor & Seltzer, 2011). Caregivers report experiencing burden related to caring for their son or daughter with ASD as they transition to adulthood (Cadman et al., 2012). Primary contributors to caregiver burden included unmet needs and comorbid psychopathology of the individuals with ASD (Cadman et al., 2012). Orsmond et al. (2006) also identified the quality of the relationship between mother and youth as an important predictor of caregiver strain. Although there is suggested to be a pattern of increased maternal well-being as their sons and daughters continue to age, distress greater than that experienced by normative samples reportedly persists (Lounds et al., 2007).

In general, results of descriptive studies suggest that outcomes for adults with ASD are poor (Cimera & Cowan, 2009; Seltzer et al., 2004) and may even worsen as adulthood progresses for these individuals (Howlin et al., 2013). However, a review by Levy and Perry (2011) revealed high variability in adult outcomes for individuals with ASD. Many studies have attempted to parse out what may lead to variability in outcomes, such as childhood symptoms

(e.g., Eaves & Ho, 2008) and IQ level (e.g., Billstedt et al., 2011; Holwerda et al., 2012). Relatively better outcomes have been reported for individuals who have at least average cognitive functioning as compared to those with co-morbid intellectual disability (ID) (Billstedt et al., 2011; Levy & Perry, 2011), although these outcomes are also variable and hard to predict (Holwerda et al., 2012). For example, even though those without ID have an increased likelihood of having a job (Billstedt et al., 2011), they still have difficulty finding work (Hendricks & Wehman, 2009), are likely to have no daytime activities (Taylor & Seltzer, 2011), and have caregivers who experience burden related to their care (Cadman et al., 2012). Additionally, although core symptoms may improve during adulthood, (Levy & Perry, 2011; Seltzer et al., 2004), this improvement is seldom associated with meaningful increases in functioning (Seltzer et al., 2004).

Research on adult outcomes for individuals with ASD emphasizes the importance of treating ASD as a lifetime diagnosis (Farley et al., 2009) and the great need for improved adult services (Eaves & Ho, 2008; Howlin et al., 2013)—in particular, autism-focused services (Taylor & Seltzer, 2011). Although there have been drastic improvements in the amount and quality of services for children with ASD in the past two decades, services for adolescents and adults with ASD have not kept pace (Farley et al., 2009; Howlin et al., 2004; Taylor & Seltzer, 2010). This population has reported needs in areas such as social participation, employment, and family well-being. Taylor and colleagues have emphasized the importance of considering families when discussing the transition to adulthood, because family members have “linked lives” (Lounds et al., 2007) and influence each other in a bidirectional manner (Taylor, 2009).

1.4 Gaps in the Literature

Although extant literature has closely examined the participation outcomes of young

adults with ASD and researchers have attempted to identify factors that contribute to outcomes, there remain substantial gaps in knowledge. First, there is some inconsistency with factors considered to influence outcomes which may be leading to confusion for families and practitioners. Awareness of what aspects of an individual's situation may contribute in the future to their adult participation outcomes is crucial information for practitioners, families, and individuals themselves, who seek avenues before and during the transition to adulthood that can help improve outcomes. Second, the extent of the role of families and the manner in which they may influence outcomes has not been thoroughly explored. Finally, there has been minimal incorporation of theory into this body of literature (Taylor, 2009), which may limit both our understanding of why the outcomes of adults with ASD are so poor as well as the ability to make meaningful progress toward improved outcomes.

CHAPTER 2: THEORETICAL AND PHILOSOPHICAL PERSPECTIVES INFORMING THE PROJECT

2.1 Theoretical Perspectives

Theory plays an important role in the development of research questions and hypotheses, and in moving a field of research forward (Clark et al., 1991; Fawcett & Downs, 1986). It can help to propel empirical findings beyond an understanding of what is happening to contemplating *why*. To date, there has been little incorporation of theory in the literature on outcomes for adults with ASD (Taylor, 2009). In the current project, I broadly used a transactional perspective from occupational science and considered specific aspects of the expectancy-value theory of achievement motivation from psychology. The occupational science concept of occupational possibilities also informed some of my thinking.

Transaction. This project broadly considered a transactional perspective of occupation—as proposed by Dickie, Cutchin, and Humphry (2006; elaborated on by Cutchin & Dickie, 2012) and based on the philosophy of John Dewey—as a guiding framework for understanding the participation of youth with autism spectrum disorder (ASD). With this perspective, one’s participation is seen as occurring through constant coordination of environment and person. Individuality and context are seen as important, but as transactionally part of one another (Cutchin & Dickie, 2012). This theory provides a broad lens through which the transition to adulthood can be viewed; specifically, providing support for looking at the participation of youth with ASD from multiple perspectives to facilitate understanding of how the many moving parts of this complex process work together. By considering more than just individual factors, I

recognize that “social and situational influences are not the backdrop to development, but are essentially parts of a whole” (Humphry, 2005, p. 42). Being open to and exploring broader transactions can contribute to expansion of how the transition to adulthood for individuals with ASD is currently considered in the literature and holds potential to inform practical work aiming to improve participation outcomes.

Expectancy-value theory. The expectancy-value theory of achievement motivation (E-V theory), researched extensively by Eccles, Wigfield, and colleagues (e.g., Eccles et al., 1983; Eccles & Wigfield, 2002; Wigfield & Eccles, 2002; Wigfield & Eccles, 2000), was derived from Atkinson’s (1964) expectancy-value model of motivation. In this theory, “Expectancies refer to beliefs about how one will do on different tasks and activities” (Eccles & Wigfield, 2002, p. 110). E-V theory posits that what individuals expect to achieve and what they value have a direct influence on their effort, persistence, choices about achievement, and performance (Wigfield & Eccles, 2000). These expectancies are also considered to be influenced by a number of personal and societal factors including family demographics, the beliefs and behaviors of others, gender role stereotypes, and self-concept of abilities (Wigfield & Eccles, 2002).

The second key piece of E-V theory is values, which are conceptualized as subjective attitudes including one’s interests, beliefs about the importance and utility of the achievement, intrinsic motivation, and perceptions of the cost (e.g., required effort) of the achievement (Wigfield & Eccles, 2002). Values are also suggested to have a direct effect on achievement outcomes and are influenced by past experiences, among other factors (Wigfield & Eccles, 2002). Finally, it is important to understand how “achievement” has been measured using this model. Eccles et al. (1983) initially studied this model looking at its relevancy for achievement in mathematics and a majority of the work in this area has focused on academic achievement

(e.g., grades, test scores) (Betz & Hackett, 1983; Hollinger, 1983). However, E-V theory has also demonstrated relevance in predicting career choices (Eccles, Barber, & Jozefowicz, 1999).

The majority of the literature on E-V theory has focused on individuals' own expectancies. Expanding upon this idea, in the current project I focused on the expectancies of caregivers of youth with ASD. Because transition planning for youth with disabilities is most often a family activity (Ankeny, Wilkins, & Spain, 2009), I hypothesized that the expectancies and values of caregivers play important role in choices made during the process, and thus in achievement of goals related to participation in young adulthood. This is likely particularly the case when the adolescent has a diagnosis such as ASD because of the increased role of the family during transition (Lounds et al., 2007). However, the manner by which caregiver expectancies contribute to transition outcomes is currently unexplored, though literature has suggested expectations can play a role in predicting outcomes (Carter et al., 2012; Chiang et al., 2012; Doren et al., 2012). Furthermore, an exploration of how the expectancies of caregivers of youth with ASD are shaped was warranted to further develop an understanding of this process with this population.

In the current project, a simplified E-V theory contributed to the research question and hypothesis for Aim 2 in which I strove to understand the extent to which expectancies mediate the relationships between youth functioning and family predictors, and outcomes for youth with ASD. E-V theory also partially informed the development of Aim 3, seeking an understanding of how caregivers of adolescents with ASD develop expectancies. Qualitative inquiry was necessary because, although E-V theory already has an empirically-driven complex model, the achievement tasks and populations which have been previously explored are quite different from those being explored here (e.g., mathematics achievement in children without diagnoses).

Therefore, an inductive approach allowed for unique insights to emerge and inform future development of a more specific model.

Occupational possibilities. Rudman's (2010) concept of occupational possibilities has been ground-breaking for the discipline of occupational science by introducing critical perspectives of power into our developing understanding of human participation. Occupational possibilities refers to, "what people take for granted as what they can and should do, and the occupations that are supported and promoted by various aspects of the broader systems and structures in which their lives are lived" (Rudman, 2010, p. 55). Her work has focused on the way that *power*—rooted in the philosophy of Foucault—plays a role in the unfolding of how people participate in activities. Rudman developed this concept using research with older adults studying the impact of media portrayals of retirement on their behavior; her work suggests that what these adults feel they can and should do is subtly controlled by social ideals portrayed in the media. Rudman described that ideals such as consumerism and individualism are supported by society and shape what has come to be understood as ideal and possible for individuals based on categorical groupings. More recently, Pergolotti (2013) developed the Perceived Occupational Possibilities scale to measure what older individuals with cancer perceive to be their occupational possibilities. Early research suggests that these perceived possibilities are more predictive of activity participation than observational measures of functional ability (Pergolotti, 2013).

The concept of occupational possibilities is related to the current project because the concept of expectations similarly reflects ideas about what individuals believe that they can and should do. However, expectations do not only reflect what people believe they can and should do, but also incorporate notions of values, motivation, and agency (i.e., what they believe they

will do). Further differentiating it from Rudman's work, the current project did not take a critical perspective. Rather, the project as a whole used a pragmatist approach aiming to understand myriad factors contributing to expectations and outcomes. Accordingly, I did not approach this project intentionally seeking to understand power relationships or remote societal forces, though I remained open to the possibility that such notions could emerge from the qualitative interviews with families.

2.2 Philosophical Position

I hold a pragmatist philosophical position which guided the broad thinking behind the current project. Pragmatism is a "philosophy of action" (Joas, 1993, p. 18); the movement began in the late 19th Century with Charles Sanders Pierce and was elaborated on by others including William James, John Dewey, George Herbert Mead, & Arthur Bentley (Joas, 1993; Maxcy, 2003). Pragmatists rejected traditional assumptions of the nature of knowledge and truth, and they challenged beliefs that we could access the *real world* through one scientific method (Maxcy, 2003). They posited that knowledge can be both constructed and real, and that different forms of knowledge result from different ways of engaging with the world (Biesta, 2010). Pragmatists believe in initiating inquiry with looking at ordinary experiences and developing research questions based on real-life problems. Accordingly, pragmatic research aims to make a difference in the world (Maxcy, 2003).

As a researcher, I acknowledge the existence of multiple truths, with a worldview—consistent with traditional pragmatists—that no single research project can arrive at an absolute truth (Maxcy, 2003). Rather, investigations provide evidence which build toward our understanding of various truths and realities, whether subjective, intersubjective, or objective (Johnson & Gray, 2010). John Dewey, a prominent American pragmatist, preferred the term

warranted assertions to ‘truth’ (Boisvert, 1998). In my research, I acknowledge that individuals and their families may hold warranted assertions based on their individual or communal beliefs and experiences (i.e., subjective). However, their assertions likely differ from more objectively-obtained assertions aiming to measure, summarize, and generalize findings across a broader population. Acknowledging the validity and gaining understanding of multiple truths can help to provide a more complete picture of the complexity of the transition process, which can contribute meaningful research findings that can have a legitimate impact on real people in society. This is highly consistent with Dewey’s perspective on the purpose of research and aligns with a transactional perspective in occupational science (Shank, 2013).

In the current project, I maintained a pragmatist perspective in general by aiming for evidence building toward multiple kinds of truths. The three manuscripts that follow (Chapters 3-5) address different research questions, each rooted in the acceptance of different types of philosophical truths. Each methodological tradition was used in accordance with its relevant philosophical tradition. This allowed for full development of findings toward each respectively sought truth, without placing broad emphasis on any one. The integrated discussion and conclusions (Chapter 6) summarizes the findings across aims from a pragmatist perspective and accordingly, considers multiple truths and connects the results to practical implications.

CHAPTER 3: LONGITUDINAL FACTORS THAT PREDICT PARTICIPATION OUTCOMES OF ADULTS WITH AUTISM SPECTRUM DISORDER: A SYSTEMATIC REVIEW OF THE LITERATURE

3.1 Introduction

The transition to adulthood comprises a period of drastic individual and situational changes (Repetti, Flook, & Sperling, 2011; Reyna, Chapman, Dougherty, & Confrey, 2012; Subotnik, 2009), made more complicated for individuals with a diagnosis affecting plans for the future (Kirk, Gallagher, Coleman, & Anastasiow, 2012; Lindstrom, Doren, Metheny, Johnson, & Zane, 2007; Turnbull, Turnbull, Wehmeyer, & Park, 2003). Successful transition is often classified using certain participation outcomes, which include vocational, relational, and daily living benchmarks (Henninger & Taylor, 2013; Seltzer, Shattuck, Abbeduto, & Greenberg, 2004; Test, Smith, & Carter, 2014; Turnbull et al., 2003). For example, a prototypical success story is an adult with steady work and social connectedness, who lives independently (or with a spouse). Yet, literature consistently describes that youth with autism spectrum disorder (ASD) struggle in these areas during the transition to adulthood as individuals with this neurodevelopmental diagnosis experience challenges related to physical, mental, and emotional needs, and societal pressures (Hendricks & Wehman, 2009; Howlin & Moss, 2013; Levy & Perry, 2011; Seltzer et al., 2004).

Individuals with ASD experience core symptoms including restricted and repetitive behaviors as well as social and communication challenges (APA, 2013). These symptoms are believed to persist throughout the lifespan, impacting participation in daily activities (Levy &

Perry, 2011; Seltzer et al., 2004). Adolescents and adults with ASD may be particularly vulnerable because services and supports often decrease in adolescence and plummet into adulthood (Levy & Perry, 2011; Lounds, Seltzer, Greenberg, & Shattuck, 2007; Taylor & Seltzer, 2011). Yet their challenges with participation in daily activities persist and may even intensify with changing personal and situational factors upon exit from high school (Taylor & Seltzer, 2010).

Further complicating the situation, the prevalence of ASD continues to rise in the U.S. (CDC, 2014). Specifically, we can expect about 196,000 more adolescents with ASD—an increase of over 120%—by the end of this decade than there were at the start, intensifying the importance of research on this topic (CDC, 2014; U.S. Census Bureau, 2012). There is a great need for a comprehensive understanding of factors that predict the outcomes of adults with ASD in order to better support successful, evidence-based transitions to adulthood.

Of particular relevance to meaningful outcomes in adulthood are an individual's extent of participation and engagement in employment, independent living tasks, and social relationships. A number of review articles published over the past decade describe these outcomes of adults with ASD (e.g., Hendricks & Wehman, 2009; Howlin & Moss, 2012; Levy & Perry, 2011; Magiati, Tay, & Howlin, 2014; Seltzer et al., 2004). In general, these reviews have identified that the vast majority of individuals with ASD experience difficulties in adulthood related to participation in these areas. Specifically, they reveal that very few adults with ASD are competitively employed, live independently, or have substantial social relationships, and even those considered to be “higher functioning” often struggle in these areas. However, these challenges in adulthood are not inevitable and some adults with ASD do achieve what are considered more successful outcomes. Some reviews of adult outcomes have also examined

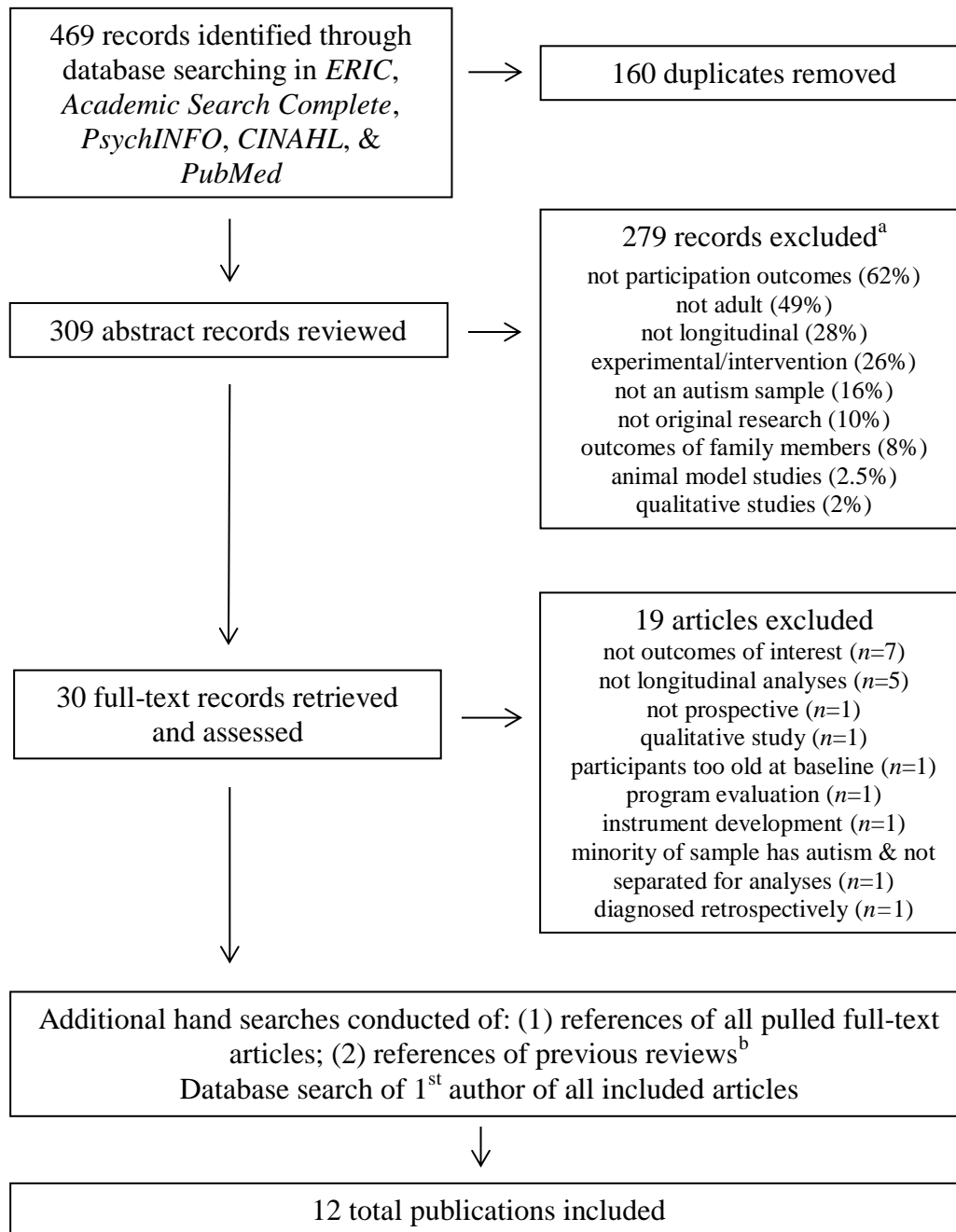
what factors may predict to participation outcomes (e.g., Magiati et al., 2014; Seltzer et al., 2004); however, this has not been the focus of the reviews, and thus predictors were not examined at great length nor in great specificity. In previous reviews, intelligence quotient (IQ) was the most commonly identified predictor of adult outcome, with childhood language abilities also often mentioned (Howlin & Moss, 2012; Magiati et al., 2014; Seltzer et al., 2004).

Despite their importance to the transition planning process, there exist no systematic reviews to our knowledge that specifically or systematically examine factors that predict participation outcomes of adults with ASD (see Holwerda, van der Klink, Groothoff, & Brouwer, 2012, for a review of predictors of employment outcomes alone). The current systematic review addresses the following research questions: (1) What pre-transition factors, identified in publications of recent longitudinal studies, predict the participation outcomes of individuals with ASD after high school? (2) What implications for transition practice and future research can be drawn from the included studies?

3.2 Method

Search procedure. To compile a comprehensive list of manuscripts identifying longitudinal factors that predict participation outcomes of adults with ASD, we conducted a systematic search of the available literature. Both content (i.e., panel of autism researchers) and process (i.e., library science specialist and research methodologist) experts reviewed the search protocol, which followed many published recommendations for high quality reviews (IOM, 2011; Moher et al., 2009; Shea et al., 2007). The search process is detailed in Figure 3.1, and began with two trained researchers performing a comprehensive database search and title/abstract record review. We pulled full-text manuscripts for all records identified by either reviewer to examine more closely. Search terms are displayed in Table 3.1; the search protocol

FIGURE 3.1: Systematic Search Process Flow Chart



Notes. ^a, Percentage totals exceed 100 because many articles were excluded for numerous reasons. ^b, Previous reviews used for reference-list checking: Hendricks & Wehman (2009); Holwerda et al. (2012); Howlin & Moss (2012); Levy & Perry (2011); Magiati et al. (2014); Seltzer et al. (2004).

TABLE 3.1: Search Terms

Diagnostic terms	Age-related terms	Outcome terms	Study design terms
Autis*	Adult*	Outcome*	longitudinal
Asperger*	Youth	Follow-up	follow-up
“Pervasive	“Young adult”	Participation	cohort
developmental	Transition*	Work*	prospective
disorder”		Job	prognostic
		Employ*	
		Vocation*	
		Occupation*	
		Social	
		Recreation*	
		Independen*	
		“Living situation”	

Notes. *, terms exploded (e.g., Autis* identified autism, autism spectrum disorder, autistic)

required relevant results for at least one term in each column (i.e., diagnostic terms, age-related terms, outcome terms, and study design terms). We excluded studies testing a specific intervention or other experimental manipulation. Additionally, although post-secondary education is relevant to transition planning, it is seen as an intermediary outcome (Holwerda et al., 2012) and thus is not of focus in the present review (though some included studies used post-secondary educational participation as an analog to employment and are reported here accordingly).

Inclusion criteria. We restricted our search to manuscripts published in the year 2000 or later. Henninger and Taylor (2013) identified the year 2000 as the beginning of the current era of outcome studies; thus, this time period was selected to reduce the inclusion of research using less rigorous, quantifiable, and reliable outcome criteria. Furthermore, some of the earliest follow-up studies in autism were published as early as the 1960s (Rutter, Greenfield, & Lockyer, 1967) and used criteria for the diagnosis of autism that differs substantially from how ASD is diagnosed today (Henninger & Taylor, 2013). Therefore, a focus on more recently-published

research provides information more directly applicable to families and transition teams making decisions in the present day. The full list of inclusion criteria used is as follows:

- (1) *Publication years*: 2000-2014
- (2) *Publication languages*: English-language records
- (3) *Publication types*: peer-reviewed research journals and official government documents
- (4) *Manuscript types*: original research reports
- (5) *Study designs*: longitudinal, cohort-based, prospective, and/or prognostic studies
- (6) *Populations*: primary population (or separated for analyses) of individuals diagnosed or classified by educational, psychological, or medical professionals with autism spectrum disorder or its variants (e.g., Asperger syndrome, autistic disorder)
- (7) *Outcomes*: data reported on predictors of participation outcomes (i.e., employment, social relationships/participation, independent living, or any combination thereof)
 - (a) Employment: report on current or former employment status (must be paid; may be full-time or less; may be supported)
 - (b) Social relationships/participation: report on status of romantic and/or friendship relationships and/or participation in recreational/social groups/activities
 - (c) Independent living: report on living situation and/or daily living skills (e.g., maintenance of personal hygiene, driving, financial management)
- (8) *Sample age at outcome*: participation outcomes reported for individuals 18 years of age or older (if age range spans across 18 years, mean age of sample must be > 18)
- (9) *Sample age at baseline*: predictors reported for individuals younger than 18 years of age (if age range spans across 18 years, mean age of sample must be < 18)

(10) *Predictors*: predictive factors measured at least 1 year prior to outcome measurement and the relationship between early predictors and participation outcome variables was directly tested using quantitative, statistical methods

Literature analysis. Upon inclusion, the first author read and thoroughly reviewed each manuscript multiple times, and extracted data relevant to the present review (see Table 3.2). Two trained reviewers rated the manuscripts on their methodological quality using Altman's (2001) recommendations for quality prognostic studies as operationalized by Holwerda et al. (2012) (see cited article for scoring protocol). The reviewers reviewed any disagreements together to reach consensus (IOM, 2011). On their 16-point scale, Holwerda and colleagues (2012) assigned manuscripts achieving ≥ 11 points to be of "high" methodological quality; we altered this slightly to account for more variability in quality and considered scores < 9 to indicate "low" quality, scores of 9-12 "moderate" quality, and manuscripts achieving scores exceeding 12 points to be of "high" methodological quality for the purposes of this review. To address our primary research question, we created a chart to display the longitudinal factors identified as statistically-significantly associated with or predictive of participation outcomes. Finally, using extracted data and information on methodological quality from the included studies, we conducted a qualitative synthesis of the findings of the review (IOM, 2011), addressing our second research question.

3.3 Results

Study details. In total, we identified 12 manuscripts meeting inclusion and exclusion criteria for this review. All included manuscripts are detailed in Table 3.2; publications describing the same research sample (or overlapping samples) are grouped together and

TABLE 3.2: Study Characteristics

Study [†]	Article	Data Source	Sample Size (% male)	Sample Diagnoses	Ages in years (range)		Sampling	Research Design		Data Collection	Outcomes				Method Quality
					Baseline	Follow-up		Groups	Waves		E	S	I	O	
1	Billstedt et al. (2005)	Gothenburg, Sweden	<i>n</i> =108 (70%)	65% autistic disorder 35% “autistic-like”	<i>M</i> =nr (<10)	<i>M</i> =25.5 (17-40)	Population	1	2	behavioral, interview, records				O	Mod.
2a	Cederlund et al. (2008)	Gothenburg, Sweden	<i>n</i> =140 (100%)	50% autistic disorder 50% Asperger syndrome	<i>M</i> =nr (<10) <i>M</i> =11.3 (5.5-24.5)	<i>M</i> =24.5 (16.1-36.1) <i>M</i> =21.5 (16-33.9)	Clinical site	2	2	behavioral, interview, records			I	O	Mod.
2b	Hagberg et al. (2013)	Gothenburg, Sweden	<i>n</i> =69 (100%)	Asperger syndrome (IQ≥70)	<i>M</i> =12.4 (6.4-24.5)	<i>M</i> =22.2 (16-36.5)		3	2	behavioral, interview, records			I		Mod.
3	Eaves & Ho (2008)	Vancouver, Canada	<i>n</i> =48 (77%)	57% autism 43% “lesser variants”	<i>M</i> =6.8 (3-12)	<i>M</i> =24 (19-31)	Clinical site	1	3	behavioral, interview, records				O	Mod.
4	Farley et al. (2009)	Utah, United States	<i>n</i> =41 (93%)	autism (IQ≥70)	<i>M</i> =7.2 (3.1-25.9)	<i>M</i> =32.5 (22.3-46.4)	Population	1	2	behavioral, interview, records				O	Mod.
5	Gillespie-Lynch et al., (2012)	nr	<i>n</i> =20 (100%)	autism	<i>M</i> =3.9 (nr)	<i>M</i> =26.6 (nr)	nr	3	4	behavioral, interview			I	O	Mod.
6	Howlin et al. (2000)	United Kingdom	<i>n</i> =19 (100%)	autism	<i>M</i> =7.0 (nr)	<i>M</i> =23.9 (21.3-26.6)	Multiple sites	2	3	behavioral, interview	E	S	I	O	High
7a	Howlin et al. (2004)	London, United Kingdom	<i>n</i> =68 (90%)	autism (PIQ ≥50)	<i>M</i> =7.2 (3.1-15.7)	<i>M</i> =29.3 (21.2-48.6)	Clinical site	1	2	behavioral, interview, records	E	S	I	O	High
7b	Howlin et al. (2013)	London, United Kingdom	<i>n</i> =60 (82%)	autism (IQ≥70)	<i>M</i> =6.8 (2.8-13)	<i>M</i> =44.2 (29-64)		1	3	behavioral, interview				O	High
8a	Chiang et al. (2013)	United States (NLTS-2: Waves 1-4)	<i>n</i> =830 ^a at baseline (nr) follow-up nr	Educational classification: autism	<i>M</i> =nr (13-16)	<i>M</i> =nr (nr) [waves every 2 years]	Stratified random (public schools nationally)	1	4	interview, records	E				Mod.
8b	Liptak et al. (2011)	United States (NLTS-2: Waves 1-3)	<i>n</i> =725 (82% ^b)	Educational classification: autism	<i>M</i> =15.4 (13-17)	<i>M</i> =19.2 (17-21)		1	3	interview, records	E	S	I		Mod.
8c	Newman et al. (2011)	United States (NLTS-2: Waves 1-5)	<i>n</i> =4,810 ^a [total sample in 12 groups]	Educational classification: autism	<i>M</i> =nr (13-16)	<i>M</i> =nr (23-26)		12	5	interview, records	E	S	I		Mod.

Notes. [†], studies using overlapping samples are grouped. nr, not reported. PIQ, performance IQ. NLTS2, National Longitudinal Transition Study-2. ^a, sample sizes rounded to the nearest 10. ^b, this article reported weighted percentages. Outcomes: E, employment; S, social relationships/participation; I, independent living; O, overall. Mod., moderate.

numbered as a single study to avoid over-generalization of results. Three samples had multiple publications associated with them; thus, eight unique studies are included. We identified relevant literature from four countries: Sweden, Canada, United Kingdom, and United States. Sample sizes ranged from 19 to over 700. As is typical in research on ASD, the majority of all samples were male (IACC, 2011); three studies exclusively included males, while the remainder had male samples representing 70 to 93 percent. Two studies (Billstedt, Gillberg, & Gillberg, 2005; Eaves & Ho, 2008) included participants with autism/autistic disorder as well as those with autism-like characteristics but not meeting for the diagnosis according to diagnostic standards at the time of study admission. One study (Cederlund, Hagberg, Billstedt, Gillberg, & Gillberg, 2008; Hagberg, Nydén, Cederlund, & Gillberg, 2013) explicitly included individuals with Asperger syndrome. Three studies (Farley et al., 2009; Hagberg et al., 2013; Howlin, Goode, Hutton, & Rutter, 2004; Howlin, Moss, Savage, & Rutter, 2013) restricted their samples to those without intellectual disabilities. Mean ages at baseline ranged from about 4 to 12 years, and at follow-up from about 19 to 44 years. Sampling occurred using population-based, clinical and community sites, and stratified random sampling. Research designs included group-comparison and single-group longitudinal (follow-up), prospective designs involving 2-5 waves of data collection. Data collection techniques primarily involved behavioral assessments, record (e.g., clinical, medical, educational) reviews, and structured caregiver interviews or surveys; most studies utilized all of these approaches, but some used only two of the three. At least one of the participation outcomes of interest in this study (i.e., employment, social relationships/participation, independent living) or a combination of the outcomes (i.e., overall outcome) were included in each manuscript. Overall outcome was the most commonly studied

(7 unique studies), followed by independent living (5 unique studies), and employment and social relationships/participation outcomes (3 unique studies each).

Methodological quality. Refer to the right-most column of Table 3.2 for methodological quality ratings. The rated quality of the majority of the included publications fell in the moderate quality range, meaning that they meet 9-12 of the quality criteria (16 in total) assessing the internal validity of the studies. Only three exceeded 12 points, demonstrating high quality (two utilizing overlapping samples) and none of the included studies ranked as low quality. The criteria facilitated assessment of the sample, follow-up, outcome, prognostic variables, and analysis techniques. The most common quality limitations across studies included: (1) entrance of participants at various stages (rather than an early uniform point across participants, as is desirable); (2) high proportions (>20%) of attrition before follow-up; (3) insufficient information about lost participants, or significant differences between those lost and those included at follow-up; and (4) the lack of acknowledgement and adjustment for treatments received. Of additional concern, some studies failed to provide sufficient detail about their analysis procedures, statistical parameters for their results, and/or explanation of their findings.

Longitudinal factors that predict participation outcomes. Upon analysis of the factors tested as predictors for participation outcomes in the included literature, we grouped the factors into five conceptual categories to aid in summarizing the findings: (1) Personal characteristics (i.e., age, gender, race); (2) Individual functioning (i.e., IQ, communication/social skills, behaviors, diagnosis/severity, independence); (3) Family context (i.e., household income, parent education, two-parent household, family support); (4) Services (i.e., career counseling, school services, attendance at special autism school); and (5) Other (i.e., peer influence [teasing], health status [overall health, epilepsy, use of medications]). Factors that significantly predicted

TABLE 3.3: Statistically Significant Predictors of Participation Outcomes Identified in Included Studies

Outcomes→	Employed ever															Employed currently															Hours worked															Working or in post-secondary ed.															Employment history															Quality of friendships															Ability to make acquaintances															Gets together with friends															Communicate with peers															Residential status															Composite independence															Daily living skills															Has driver's license/permit															Has checking account or credit card															Howlin criteria															Composite from FHS															Lotter criteria															Mixed composite†																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																												
↓ Predictive Factors	Employment					Social Relationships					Independent Living					Overall Outcomes																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																												
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Notes. Numbers refer to corresponding studies (see Table 3.2). Bolded numbers indicate high quality studies. FHS, family history schedule. †, mixed composite was based on domains of language, friendship, independence, and stereotyped behaviors.

participation outcomes in the included studies are displayed in Table 3.3 with the corresponding study number (refer to Table 3.2 for study numbers). Throughout this review, significance refers to statistical significance as determined and reported within each publication.

Personal characteristics. Personal characteristics (age, gender, and race) were only found to be significant in study 8—publications from the National Longitudinal Transition Study-2 (NLTS2; IES, n.d.). Liptak, Kennedy, and Dosa (2011) identified age at baseline as a significant predictor of how often friends telephoned (social) at follow-up; the older participants were, the less likely they were to be telephoned by friends. Relevant in this situation is the rigid timing in the design of Study 8 (such that, age at wave 1 directly relates to age at wave 3), and it is likely that it is actually the age at follow-up that is predictive in this case. African American race was identified as a negative predictor of how often participants got together with friends, and white race as a positive predictor of having a driver's license or permit (Liptak et al., 2011). Gender was identified in study 8 as a predictor of both whether participants were employed ever and how often they got together with friends. Chiang, Cheung, Li, and Tsai (2013) reported that males were less likely to be employed and Liptak et al. (2011) that males got together with friends less often. Of note, gender was found to be a non-significant predictor of overall outcome by Billstedt et al. (2005). No other personal characteristics were reported as significant or non-significant predictors of participation outcomes in the manuscripts.

Individual functioning. Level of individual functioning (IQ/cognition, communication/social, diagnosis/severity, independence) was the most-studied predictor and all eight studies identified at least one area of individual functioning to be predictive of longitudinal participation outcomes. One additional predictive factor related to individual functioning—repetitive behaviors—was explored in one study, but repetitive behaviors were not found to be a

significant predictor of overall outcome (Howlin et al., 2013). The individual functioning factors were often, but not always, measured using standardized behavioral assessments; however, most studies utilized a combination of multiple measures across participants for various reasons.

IQ/cognitive functioning. Intellectual functioning has been heavily studied as a predictor of outcomes for individuals with ASD. Higher IQ was identified to predict employment in two included studies. Howlin et al. (2004)—a high quality study—found that individuals with an IQ ≥ 70 (measured by various standardized assessments) had higher levels of work than individuals with IQs in the 50-69 range. From the NLTS2 (study 8), Liptak et al. (2011) identified that having an educational classification of intellectual disability negatively predicted engagement in employment or post-secondary education and Chiang et al. (2013) found parent-reported intellectual disability to negatively predict whether participants were employed ever. Quality of friendships and residential status were also identified by Howlin et al. (2004) to be negatively predicted by lower IQ. Gillespie-Lynch et al. (2012) found that higher IQ predicted higher skills in activities of daily living as measured by the Vineland Adaptive Behavior Scales (VABS; Sparrow, Balla, & Cicchetti, 1984).

Finally, five studies—including one of high quality—reported positive relationships between intellectual functioning and overall outcomes. Howlin et al. (2013) and Farley et al. (2009) found full-scale IQ scores to significantly predict overall outcome scores. Howlin et al. (2004) found that an IQ ≥ 70 (versus those in the 50-69 range) positively predicted overall outcome score, but that having an IQ ≥ 100 did not have an additional positive impact on overall outcome (versus those in the 70-99 range). Gillespie-Lynch et al. (2012) identified that *change* in developmental quotient score over time (improvement from childhood to adolescence) positively predicted overall outcome. However, these authors did not find early developmental

quotient score on its own to be a significant predictor (Gillespie-Lynch et al., 2012). Two additional studies (Billstedt et al., 2005; Eaves & Ho, 2008) reported an identified relationship between IQ and overall outcomes, but no parameter or significance estimates were reported.

Communication/social functioning. One included study identified a relationship between problems conversing and whether or not participants were employed or in post-secondary education at a later time point (Liptak et al., 2011). No other studies reported looking at communication or social functioning as a longitudinal predictor of employment outcomes. The same study identified predictive ability of communication/social skills to social relationships/participation outcomes, finding how well youth communicated to positively predict both how often friends telephoned and how often youth got together with friends over the course of a year (Liptak et al., 2011). Social assertion and clarity of speech were also identified as predictors of how often friends telephoned (Liptak et al., 2011), though the association with clarity of speech appears to be contrary to what would be expected (negative standardized beta coefficient reported though not explained in the manuscript).

One study identified a significant relationship between communication skills and independent living outcomes. Gillespie-Lynch et al. (2011) found language age equivalent at their first time point ($M=3.9$ years of age) to significantly predict the later daily living skills scores on the VABS (Sparrow et al., 1984). Of note, this study also examined the predictive potential of initiation of joint attention and response to joint attention at the same time point and found that these social-communication factors did not significantly predict daily living skills at follow-up.

Although Gillespie-Lynch and colleagues (2012) also did not find a relationship between early initiation of joint attention and later overall outcomes, they did identify responsiveness to

joint attention and language age equivalent at time one as well as change in language age equivalent from childhood to adolescence to be significantly correlated with overall outcome. Howlin et al. (2013) found reciprocal social interaction score on the Autism Diagnostic Instrument (ADI; Le Couteur et al., 1989) to be the strongest predictor of overall outcome in mid-late adulthood; though it is important to note that although the participants were initially assessed in early childhood, the ADI was performed retrospectively at a later time point (when participants were 7 to 46 years old). These authors also identified that with reciprocal social interaction in a multivariate model, childhood language scores (ADI communication domain) were no longer significant in their analyses (Howlin et al., 2013). Howlin, Mawhood, and Rutter (2000) found that Peabody Picture Vocabulary Test (PPVT; Dunn, Dunn, Bulheller, & Häcker, 1965) score at time one ($M=7$ years of age) accounted for 32% of the variability in overall composite score at follow-up. Billstedt et al. (2005) also reported that communicative phrase speech at age 6 was correlated with better outcomes, though the manuscript does not report on the methods used or statistical parameters (including significance).

Diagnosis/severity. Multiple studies have compared longitudinal predictive factors of participation outcomes across individuals with ASD and those with various other diagnoses. Articles from the NLTS2 (study 8) compared outcomes across individuals with eleven other educational diagnostic classifications including learning disability, specific language impairment, sensory impairments, brain injury, multiple disabilities, and other health impairments. Individuals with an educational classification of autism have been found to have less participation and independence than many of these groups on multiple participation outcomes including educational (i.e., hours worked, employed currently, employed ever, and employed or in post-secondary education), social relationships/participation (i.e., sees friends weekly and

communicates with peers online), and independent living outcomes (i.e., residential independence, having a driver's license or permit, and having a checking account or credit card) (Newman et al., 2011). They did not differ from many of the other classifications on number or duration of jobs, types of jobs held, or wages/benefits among those who had held at least one job (Newman et al., 2011).

Howlin et al. (2000) identified significant differences in employment history, ability to make acquaintances, independent living (i.e., living arrangements, VABS daily living skills scores, and composite independence), and overall (composite of friendships, independence, language, and stereotypies) outcomes between a group of men diagnosed with developmental receptive language disorder in childhood (7-8 years of age) and those with autism ($M=7$ years of age). However, in this study, the two groups did not differ in friendship levels alone at follow-up (Howlin et al., 2000). Cederlund et al. (2008) identified significant differences between independent living and overall outcomes of individuals diagnosed with Asperger syndrome versus autistic disorder at baseline. When comparing outcomes of adults with Asperger syndrome and persistent non-verbal learning disorder (NLD), childhood NLD, and those who never had NLD, Hagberg et al. (2013) did not find significant differences in independent living outcome (VABS daily living skills score).

Finally, severity of autism was explored as a predictor of overall outcome, but not of individual participation outcomes, in the included studies. Howlin et al. (2013)—a high quality rated study—identified baseline ADI algorithm total to be a strong, significant predictor of overall, composite outcome; though, again, ADI was performed retrospectively in this study. Additionally, Eaves and Ho (2008) reported that early Childhood Autism Rating Scale (CARS;

Schopler, Reichler, & Renner, 1988) score predicted overall outcome, though when combined with verbal IQ in a multivariate model, autism severity became statistically non-significant.

Independence. Liptak et al. (2011) explored the relationship between levels of independent-living skills at wave one of the NLTS2 and social and independent living outcomes. Higher ratings on functional abilities positively predicted both how often friends telephoned and how often youth got together with friends in the past year (Liptak et al., 2011). Independence in activities of daily living also positively predicted whether or not individuals with ASD had a driver's license or permit. No other included studies reported examining relationships between independence level and participation outcomes over time.

Family context. Publications from the NLTS2 (study 8) also explored the relationship between family context variables (i.e., household income, parent education, two-parent household, parent expectations, and family support) and participation outcomes (employment, social relationships/participation, and independent living). Household income positively predicted employment; specifically, being above the poverty level predicted whether or not individuals had been employed ever (Chiang et al., 2013) and household income predicted whether individuals were currently working or in post-secondary education (Liptak et al., 2011). Parental involvement in school also positively predicted whether individuals were currently either working or in post-secondary education (Liptak et al., 2011). Liptak et al. (2011) also identified that the education level of the head of household (negative association presented, but not explained), the amount of family support, and a two-parent home predicted how often youth got together with friends. Additionally, these authors found being above the poverty level, a two-parent household, and parental involvement in school to predict whether individuals had a driver's license or permit (Liptak et al., 2011). Parent expectations of whether youth would have

a paid job in the future were examined by Chiang et al. (2013) and found to independently differentiate those who later were employed, but this variable was not significant in a multivariate model. No other included publications reported exploring relationships between family context variables and participation outcomes.

Services. Publications from the NLTS2 (study 8) reported significant relationships between services and participation outcomes. Specifically, Chiang et al. (2013) identified having received career counseling as positively predicting whether individuals had been employed ever and Liptak et al. (2011) identified the number of school services received to positively predict whether or not individuals had a driver's license or permit. Howlin et al. (2013) examined whether there was a relationship between attending special autism schools (versus nonspecialist schools) and long-term overall outcomes, finding non-significant results. No other included studies reported examining relationships between services and participation outcomes.

Other. Additional factors—peer influence and health status—were explored in relation to participation outcomes. Peer influence was examined in one publication (Liptak et al., 2011); specifically, having been teased in school was associated with whether or not individuals were employed or in post-secondary education at outcome (though, again, the direction of this relationship is unclear in the publication and not explained). Liptak et al. (2011) identified general health and not using prescription medicine as positive predictors of employment outcome (employed or in post-secondary education). Health status was also found to positively predict how often youth got together with friends in the same study (Liptak et al., 2011). Additionally, one study (Billstedt et al., 2005) looked particularly at presence of epilepsy at baseline and did not find it to significantly predict overall outcome.

3.4 Discussion

In this review, we present a summary of longitudinal studies published in the past 15 years which identify predictors of participation outcomes (i.e., employment, social relationships/participation, independent living, or a combination thereof) for individuals with ASD. Special education policies in the U.S. (i.e., IDEA, 2004) mandate effective planning for post-high school life including education, employment, adult services, independent living, or community participation. To do this requires knowledge of what aspects of an individual's life and experiences might contribute to expected outcomes in order to identify areas to focus on in the planning process and to develop promising support plans. We argue that this information, combined with priorities and goals identified by the transitioning youth and their family (Kim & Turnbull, 2004), is necessary for development of an effective transition plan.

Only eight unique studies met inclusion criteria for the present review, thus demonstrating there is little current research (published in the past 15 years) about factors *before* high school exit that give us information about what we might expect for individuals with ASD *after* high school. This limits the transition planning process and may result in confusion and stress for families and individuals (Seltzer, Krauss, Orsmond, & Vestal, 2001). The knowledge generated in this review is critical for informing evidence-based transition practices (Mazzotti, Rowe, Cameto, Test, & Morningstar, 2013) and development of more effective service provision for this population both before and after transition (Test et al., 2014). In the following sections, we discuss the implications of the present review in terms of the influence of study methodologies on interpretation of results and the application of the identified predictive factors to transition planning for individuals with ASD.

Influence of study methodologies on interpretation. Practical implications of individual research publications and research reviews hinge on the study design and quality of individual publications and the relative strengths and weaknesses observed across the included body of research (IOM, 2011). For the purposes of this review, we considered studies meeting fewer than nine of 16 quality criteria to be of low methodological quality. However, none of the included studies fell into the low quality category for this review. It appears that our inclusion criteria may have screened out the low quality studies, particularly in regard to publication date. It is likely that the rigor required for publication of these studies has increased in recent years in accordance with the dramatic rise in publications on ASD (IACC, 2012). The majority of the included studies met criteria for moderate methodological quality (i.e., meeting 9-12 criteria) and two studies—resulting in three included publications—met criteria for high quality. There are a number of aspects of the publications included in the present review that impact the manner in which interpretations can be drawn including sample characteristics and data collection and analysis techniques.

Sample characteristics. Three of the eight unique studies in the present review are associated with multiple included publications. Overlapping samples were studied in Sweden (Cederlund et al., 2008; Hagberg et al., 2013), the United Kingdom (Howlin et al., 2004; Howlin et al., 2013), and the United States (Chiang et al., 2013; Liptak et al., 2011; Newman et al., 2011). Conducting multiple analyses on the same (or an overlapping) sample can allow for more in-depth and complex research questions to be asked and answered. Yet, this practice also increases the statistical likelihood of false discovery (i.e., type I error) (Young & Karr, 2011). Type I error is also more likely when analyses lack theoretical rationale and specific *a priori*

hypotheses (Banerjee, Chitnis, Jadhav, Bhawalkar, & Chaudhury, 2009); Taylor (2009) identified lack of theory as a concern in this body of research.

Additionally, sample size can affect the extent to which predictor variables meet significance in individual analyses and how generalizable the findings are. Studies with smaller samples (e.g., Gillespie-Lynch et al., 2012; Howlin et al., 2000) may under-identify factors and also may be less-representative of broader populations. Alternately, larger sample sizes (e.g., Chiang et al., 2013; Liptak et al., 2011; Newman et al., 2011) may find significance in factors without taking into account the magnitude of the effect. Gender representation in the samples is another aspect that influences interpretation. ASD is consistently described to be more common among males than females; however, only three studies recruited a male to female proportion within a 10% of current population estimates (4.5 to 1, or 22%; CDC, 2014). Additionally, this practice limits the ability of researchers to examine predictors of adult participation outcomes that may be unique to females with ASD. The Interagency Autism Coordinating Committee (IACC, 2011, 2012, 2013) described a pressing need for more research on all aspects of ASD among females, which is yet unmet in this body of literature.

The effects of sample attrition in longitudinal studies can also substantially influence factors identified as statistically significant (Altman, 2001). Publications from five of the eight study samples (Cederlund et al., 2008; Eaves & Ho, 2008; Gillespie-Lynch et al., 2012; Hagberg et al., 2013; Howlin et al., 2013; Liptak et al., 2011) lost more than 20% of their sample from baseline to follow-up. When dealing with attrition, it is considered best practice to compare attriters and non-attriters on baseline variables to determine the extent to which the two groups may differ (Altman, 2001). Some included studies provided this information, finding either differences (Gillespie-Lynch et al., 2012) or no significant differences (Howlin et al., 2013),

while others did not provide sufficient information (Cederlund et al., 2008; Chiang et al., 2013; Eaves & Ho, 2008; Hagberg et al., 2013; Liptak et al., 2011; Newman et al., 2011). However, even with comparable characteristics at baseline, there remains potential for attrition-related study bias (Young & Karr, 2011).

Finally, differences in diagnostic procedures and inclusion criteria related to diagnosis and functional level employed across studies may be relevant for our interpretations. The studies in the present review included participants who were diagnosed using different procedures and/or had varying diagnoses (e.g., autistic disorder, Asperger syndrome). Although this may have posed a challenge, we identified similar predictors across studies. This may imply that although outcomes may differ, predictors of outcomes have relevancy across the autism spectrum (i.e., despite marked heterogeneity in the diagnosis).

Data collection and analysis. Data collection and analysis techniques used in prognostic studies can influence generalizability to broader populations and implications for practice (Altman, 2001). Many of the included studies used multiple parent-report measures. Using only proxy-report can limit the generalizability of the findings because of the potential for decreased objectivity and fidelity across responders, especially when asking particular questions—for example, about level of parent support. However, the availability of more objective, observable research measures is limited, especially for meaningful adult outcome measures (Henninger & Taylor, 2013). In fact, many constructs of importance to understanding adult participation outcomes are not observable behaviors and cannot be measured objectively. Previous authors have suggested that subjective experiences may be equally as important to understanding successful transitions to adulthood (Henninger & Taylor, 2013; Turnbull et al, 2003).

The time point of first data collection is a critically important aspect of prognostic studies because to best understand the influence of predictive factors, they should be measured at an early, uniform point in time across participants (Altman, 2001). This is difficult criteria to achieve in prognostic research with people with ASD because of availability of participants (particular in earlier studies when prevalence was lower) and varying ages of diagnosis; even the studies that entered participants at time of first diagnosis included a wide age range at baseline. The diagnosis of ASD is commonly delivered when a child is between one and three years of age in the United States (CDC, 2014); however, the time of diagnosis can vary drastically based on numerous factors including family beliefs (Harrington, Patrick, Edwards, & Brand, 2006), access to services (Daley, 2004), community awareness of ASD (Fountain, King, & Bearman, 2011), and the extent to which an individual's symptoms affect the ability to meet their environmental or situational demands (APA, 2013).

The lack of investigation of treatment effects is another methodological challenge to the value of prognostic studies (Altman, 2001). The majority of the studies included in this review did not include amount or type of treatment as predictors or covariates in their longitudinal predictive or correlational analyses. However, it is highly likely that all participants included in all of these studies received at least some services, especially because the majority of sampling occurred at clinical or educational sites. Understanding the impact of interventions/services is critically important for planning future provision of services as well as for understanding how services may influence the relationships between predictors and outcomes. For example, it is likely that the influence of family income on outcomes is related at least partially to service availability and use.

Finally, to develop a complete understanding of early factors relevant to adult outcomes, it is critical to explore those factors found to be both significant *and* non-significant (Altman, 2001). The present review importantly included available non-significant results in the qualitative summary of the results. However, some studies may not report longitudinal factors that they explored and found non-significant and/or studies without significant findings may not have been published (i.e., publication bias). Without evidence to the contrary, families and practitioners may falsely assume non-significant factors have relevance and make inappropriate predictions or plans for transition.

Application of identified predictive factors to transition planning. Transition planning is a required and important part of educational services for exceptional individuals in the U.S., including those with ASD (IDEA, 2004). Recent publications argue the importance of evidence-based transition practices (Mazzotti et al., 2013; Test et al., 2014), which could be better informed with clarified understanding of the role of predictive factors on the post-school outcomes of individuals with ASD. Knowledge of the evidence on predictive factors, as generated in the present review, can help in determining service needs during early and middle childhood as well as in anticipation of support during and after the transition to post-secondary experiences. In the present review, we identified five categories of predictive factors found to significantly predict participation outcomes for individuals with ASD after high school: personal characteristics, individual functioning, family context, services, and other. It is especially important to note, however, that *only* the individual functioning category reflected significant predictive factors found across multiple study samples; the remaining categories reflect significant predictors found in publications using the NLTS2 dataset (study 8).

Predictive factors identified across studies. Predictive factors related to an individual's level of functioning at an earlier time point emerged as significant in many of the included longitudinal studies. IQ and cognition, which have been previously declared the most significant predictors of outcome (e.g., Magiati et al., 2014; Seltzer et al., 2004), were also identified in the included studies. Early cognitive status was identified as a predictor of employment (Chiang et al., 2013; Howlin et al., 2004; Liptak et al., 2011), social participation/relationships (Howlin et al., 2004), and independent living outcomes (Gillespie-Lynch et al., 2012). Additional relationships were identified with overall outcome (Billstedt et al., 2005; Eaves & Ho, 2008; Howlin et al., 2013), with two caveats to consider: (1) having an IQ above 70 was significant, but having an IQ above 100 may not make a difference beyond that (Howlin et al., 2004), and (2) one study identified *change* in intelligence from childhood to adolescence as more relevant than childhood IQ alone (Gillespie-Lynch et al., 2012). Practitioners involved in transition planning should maintain awareness of the current and past IQ of the transitioning youth (and how it has changed over time), as well as the functional implications of their IQ, as this may help guide the amount and types of supports needed for post-transition success in employment, social interactions, and independent living activities. However, it is critical to recognize that multiple studies have shown a high IQ does not equate to success in participation outcomes after high school (Howlin et al., 2004; Howlin & Moss, 2012; Taylor & Seltzer, 2011), and attention must be paid to individuals with ASD who have high IQs so they do not “fall through the cracks” (Taylor & Seltzer, 2011).

Early communication and social skills are another commonly reported longitudinal predictor of outcome for adults with ASD (Magiati et al., 2014; Seltzer et al., 2004) that were also identified in the current review. Early communication and social skills were found to be related

to employment (Liptak et al., 2011), social participation/relationships (Liptak et al., 2011), independent living (Gillespie-Lynch et al., 2012), and overall (Billstedt et al., 2005; Gillespie-Lynch et al., 2012; Howlin et al., 2000; Howlin et al., 2013) outcomes. Gillespie-Lynch et al. (2012) looked at a more unique social-communication factor—joint attention—and identified that early response to joint attention related to later overall outcomes but neither response to nor initiation of joint attention predicted independent living skills. Awareness of the influence of social and communication skills on post-school outcomes should help guide the provision of additional services to support these skills leading up to the transition as well as adaptations and/or supports that may be needed for success during and after transition.

Diagnosis and severity of diagnosis were also identified as predictors in the included studies. The outcomes of individuals with ASD are continually found to be poorer than those of individuals with many other diagnoses (Howlin et al., 2000; Newman et al., 2011). Thus, it is necessary to view students with ASD undergoing transition through a slightly different lens and provide diagnosis-specific, individualized services to support transition success (Taylor & Seltzer, 2011).

Finally, level of independence earlier in high school was found to predict to post-school social and independence outcomes (Liptak et al., 2011). Again, this information should help guide the provision of services; however, more research is needed to understand what specific services are most effective in supporting more successful post-school outcomes.

Predictive factors identified as significant in NLTS2 publications. As previously stated, publications resulting from the NLTS2 dataset alone produced the remainder of the predictive factors identified as statistically significant which substantially limits the extent to which we can generalize the results. Seltzer et al. (2004) also highlighted the limited inclusion of

environmental factors to understand the outcomes of ASD; despite the elapsed decade, only one major study has contributed to our understanding of these factors. Although the NLTS2 included a nationally-representative sample, evidence-based practice is best supported with multiple studies (Mazzotti et al., 2013; Odom et al, 2005) which could ensure these findings are not idiosyncratic to the NLTS2 sampling or data collection procedures.

Regarding race, NLTS2 participants of African American race experienced more negative outcomes related to social participation/relationships and those of white race experienced more positive outcomes related to independent living (Liptak et al., 2011). Race was not included as a factor in any of the other study samples; in fact, most other studies did not even describe the racial make-up of their sample, likely due to minimal or no racial diversity in their samples. Racial disparities are a problem in health services provision for individuals with ASD (IACC, 2011) and this must be given greater attention in future research and in determining the post-school needs of individuals from minority backgrounds. Likewise, gender was only identified as significant in NLTS2 publications; males were suggested to have more negative employment (Chiang et al., 2013) and social participation/relationship outcomes (Liptak et al., 2011). Billstedt et al. (2005), however, found gender to be non-significant and Seltzer et al.'s (2004) review highlighted uncertainty in the direction and relevance of gender to outcomes of adults with ASD. More research is needed to clarify the role of gender on outcomes, though the results of the present review suggest males with ASD may benefit from enhanced transition support to promote positive participation outcomes.

In general, studies from the NLTS2 showed increased family resources and involvement predict improved employment and social participation/relationship outcomes (Chiang et al., 2013; Liptak et al., 2011). NLTS2 studies also demonstrated that high school services positively

predicted employment and independent living outcomes (Chiang et al., 2013; Liptak et al., 2011), but Howlin et al. (2013) did not find autism-specific education to significantly predict overall outcomes. These findings should be encouraging to those involved in transition planning because the important role of families is often promoted, support services are believed to be beneficial, and inclusion in general education is generally believed to be beneficial (Mazzotti et al., 2013; Test et al., 2014); these practices are all further supported by the present review for students with ASD.

Finally, health status positively predicted employment and social relationship/participation outcomes in one NLTS2 publication (Liptak et al., 2011), but Billstedt et al. (2005), who looked specifically at history of epilepsy as a predictor, did not find a significant relationship. Thus, the health of individuals with ASD should be considered when developing a transition plan including coordination with community health services/organizations when relevant (Johnson, Stodden, Emanuel, Luecking, & Mack, 2002).

Limitations and recommendations for future research. There are a few points of consideration relative to the nature of the present review that need mention. First, although it is considered best practice to conduct searches in multiple languages and include articles published in languages other than English (IOM, 2011), we did not do this in the current review for practical purposes. Thus, reports published in any language other than English were not explored here which could hold potential to limit findings relevant in other cultures; however, there were studies from four countries represented in the present review. Second, it is important to note that we are aware of additional methodologically strong research relevant to outcomes of adults with ASD that was excluded from this review due to the inclusion criteria around participant ages at baseline and follow-up. This was done purposefully to isolate pre-high school

factors that predict post-high school outcomes for utmost relevance to transition planning; however, data from those studies may have contributed additional factors not explored here. Finally, limiting the included manuscripts to those published in 2000 or later has both limitations and strengths for the review. It clearly limited the number of publications included in the review, thus potentially diminishing its perceived importance. However, it provides more specific and practically-relevant information for those involved in transition planning for individuals with ASD due to its currency and the increased rigor of this body of literature (Henninger & Taylor, 2013).

This review highlights the pressing need for more research about adult outcomes for females with ASD; increased understanding of females with ASD has also been identified by the IACC (2011, 2013). Additionally, there is a need for more research on racially and socioeconomically diverse groups relevant to outcomes for adults with ASD. Currently, there is minimal understanding of racial and socioeconomic differences in outcomes, but we are aware of disparities regarding age of diagnosis (Fountain et al., 2011) and service provision (IACC, 2011) which likely influence outcomes. Furthermore, there is a need for more research related to environmental influences on outcomes. The research presented in the current review spanned four countries, and though similar predictors were identified, previous research has suggested outcomes may differ across regions (e.g., Farley et al., 2009) providing evidence of the potential for environmental contributions. Finally, in addition to better understanding of the outcomes presented in this review, there exists a critical need for more research to develop evidence-based transition planning practices (Test et al., 2014). Future research should follow Mazzotti et al.'s (2013) recommendations for meeting quality, complexity, and capacity standards in effective transition research.

Although some literature suggests that predictors may differ across outcome areas (e.g., Liptak et al., 2011), in this review, we identified similar predictors across participation outcome categories. This suggests there may be similarity in the mechanisms and processes by which the identified predictors influence outcomes across these categories (i.e., employment, social relationships/participation, independent living). Another possibility is that participation outcomes influence each other, such that success or struggle in one area can differentially affect other outcomes (e.g., having a job allows for residential independence). Future research should explore the transition to adulthood using multiple methods to better understand outcome predictors within the dynamic process as a whole. Additionally, statistical approaches using mediation and/or moderation analyses may help clarify the extent to which outcomes influence each other in uni- or bi-directional ways. The identification of similar predictors across participation outcome categories also provides evidence to support the relevance of studying overall outcomes—already popular in the literature (Henninger & Taylor, 2013; Taylor, 2009)—which combine employment, social, and independent living status in longitudinal outcome studies.

3.5 Conclusions

Through systematic review of the literature, we consistently found factors within the category of level of individual functioning (i.e., IQ, communication/social skills, behaviors, diagnosis/severity, independence) to be statistically significant longitudinal predictors of participation outcomes of individuals with ASD after high school. Additional research is needed to better understand the ways in which the factors related to personal characteristics, family context, services, health, and peer influence contribute to participation outcomes of individuals with ASD after high school. Additionally, there was a lack of explored variables related to

family processes and other potential environmental influences, which warrant further investigation. However, transition planning must carry on in practice without this additional evidence. In the meantime, those involved in transition planning should ensure they consider more than just an individual's level of functioning when considering post-secondary plans related to participation outcomes. It is also recommended that additional factors be taken into account including personal characteristics, family context, services already received, health, and peer influence. This is not to say that factors such as gender, race, household income, or health status *determine* one's outcomes, but that they should be considered in the planning process and used to contribute to an overall individualized plan. Using the evidence reviewed in the present paper, transition teams can survey all of the factors related to a student's situation to develop a realistic plan for the amounts and types of support needed to prepare each individual for life after high school.

CHAPTER 4: PARENT EXPECTATIONS MEDIATE OUTCOMES FOR YOUNG ADULTS WITH AUTISM SPECTRUM DISORDER

4.1 Introduction

The transition to adulthood for individuals with autism spectrum disorder (ASD) has become a topic of great interest, importance, and immediacy within the interdisciplinary autism field in response to growing concern in the community (Interagency Autism Coordinating Committee, 2013). Extant research suggests individuals with ASD often struggle during the transition to adulthood and have numerous needs unmet by current educational and community support services (Howlin & Moss, 2012; Levy & Perry, 2011). Specifically, limited outcomes have been reported in multiple domains of adult functioning including employment, residential independence, and social participation. Furthermore, there is an expected increase of over 120% in individuals with ASD aging out of the secondary education system this decade (based on available estimates from Centers for Disease Control, 2014 and U.S. Census Bureau, 2012), placing additional stress on an already burdened adult services system and leaving many individuals and their families with limited resources to support success in adulthood (Eaves & Ho, 2008; Henninger & Taylor, 2013; Howlin & Moss, 2012; Taylor & Seltzer, 2011). Thus, there is a great need to understand factors that influence outcomes of adults with ASD—and complex relationships among those factors—to enable the promotion of improved outcomes.

Adult outcomes. Three key areas of adult functioning have been explored repeatedly in the autism literature: employment, residential independence, and social relationships (Taylor,

2009). Often these domains are combined or merged to create an overall criterion-based rating to broadly categorize the outcomes of study participants (Henninger & Taylor, 2013). Early literature from Lockyer and Rutter (1969) suggested the vast majority (75%) of adults with ASD had poor outcomes across these areas and most studies up to the present day continue to report positive outcomes for only a minority of participants (~0–48%; Cederlund, Hagberg, Billstedt, Gillberg, & Gillberg, 2008; Eaves & Ho, 2008; Farley et al., 2009; Gillespie-Lynch et al., 2012; Howlin, Goode, Hutton, & Rutter, 2004; Howlin, Mawhood, & Rutter, 2000). Comparisons have also been drawn between the outcomes of adults with ASD versus those with other diagnoses. Although the purpose of the current study is not to compare diagnostic groups, this information helps add context around the notion that adults with ASD seem to face unique challenges regarding participation in employment, daily living independence, and social relationships. Struggles in adulthood may be related to particular aspects of the diagnosis, increased behavior and psychological problems in adulthood, changes in the environment and contextual demands, and decreases in support over time (Levy & Perry, 2011; Taylor & Seltzer, 2011). Despite improvements in services and broadening of the autism spectrum, the reported outcomes of adults with ASD remain generally poor and strikingly consistent across outcome domains.

Employment. Employment is the most heavily studied outcome for adults with ASD and studies continually suggest that individuals with ASD have low rates of employment (e.g., Carter, Austin, & Trainor, 2012; Holwerda, van der Klink, Groothof, & Brouwer, 2012; Shattuck et al., 2012). They are also reported to work in segregated settings (Carter et al., 2012), at menial jobs (Taylor & Seltzer, 2011), and for low wages and hours (Taylor & Seltzer, 2011), even when compared to individuals with other disabilities (Cimera & Cowan, 2009; Roux et al., 2013).

Shattuck et al. (2012) suggested that individuals with ASD may be particularly at risk for employment struggles within the first two years after leaving high school. However, a long-term follow-up study by Howlin, Moss, Savage, and Rutter (2013) suggested that limited employment may persist long-term and a longitudinal trajectory analysis by Taylor and Mailick (2014) identified a significant decreasing trajectory of vocational participation over a 10-year period for adults with ASD. This limited employment can have a negative effect on the finances and well-being of adults with ASD and their families, as well as placing strain on government funds and services.

Residential independence. Outcome studies commonly report that the vast majority of adults with ASD live with their parents or in other supported situations, with very few attaining complete residential independence (Farley et al., 2009; Henninger & Taylor, 2013; Howlin et al., 2013; Howlin et al., 2003; Howlin et al., 2000; Levy & Perry, 2011; Taylor & Seltzer, 2011). Comparative studies have suggested that individuals with ASD had less residential independence than adults with Down syndrome (Esbensen, Bishop, Seltzer, Greenberg, & Taylor, 2010) and youth with other educational classifications including intellectual disabilities, traumatic brain injury, learning disabilities, speech-language impairments, sensory impairments, or emotional disturbances (Newman et al., 2011). Related to residential independence, daily living skill independence was shown to increase in adolescence and early adulthood, but level-off and then begin to decline around 30 years of age in a longitudinal trajectory analysis (Smith, Maenner, & Seltzer, 2012). Because many adults with ASD live in supported settings and have limited engagement in employment, they may have minimal motivation or need to expand or even maintain their skills and independence over time.

Social participation. Social participation outcomes reported across studies point to poor

social integration among young people with ASD. Specifically, a number of studies have reported that a large proportion of the individuals they studied were described to have no friendships (e.g., Billstedt, Gillberg, & Gillberg, 2011; Liptak, Kennedy & Dosa, 2011; Orsmond, Kraus, & Seltzer, 2004) and to be socially isolated (Liptak et al., 2011). Lack of friendships in this population has been associated with loneliness, which is also related to increased levels of depression and anxiety (Mazurek, 2014). Their participation in social activities with peers is typically limited, especially regarding group activities (Shattuck et al., 2011); however, when they do participate, it is typically restricted within groups of people with disabilities (Shattuck et al., 2011). Comparison studies have demonstrated that youth with ASD have significantly less social participation than youth with Down Syndrome (Esbensen et al., 2010) and other classifications such as intellectual disability, learning disability, and emotional and behavioral problems (Orsmond, Shattuck, Cooper, Sterzing, & Anderson, 2013).

Factors that predict outcomes. Despite the apparent consistency in identifying poor outcomes, review authors have highlighted that there is variability in outcomes and some adults with ASD do attain successful employment, residential independence, and social relationships (Hendricks & Wehman, 2009; Howlin & Moss, 2012; Levy & Perry, 2011; Selzer et al., 2004). Thus it is also important to closely examine factors that contribute to adult outcomes in order to inform efforts to improve positive outcomes for more individuals. Extant literature has identified numerous predictors of outcomes for adults with ASD including: cognition (Anderson, Liang, & Lord, 2014; Farley et al., 2009; Howlin et al., 2004; Howlin et al., 2013), language/communication skills (Gillespie-Lynch et al., 2012; Howlin et al., 2013; Liptak et al., 2011), diagnostic severity (Eaves & Ho, 2008; Howlin et al., 2013), household income (Liptak et al., 2011), parent education (Liptak et al., 2011), parent expectations (Chiang, Cheung, Li, &

Tsai, 2013), race (Liptak et al., 2011), gender (Chiang et al., 2013; Liptak et al., 2011; Migliore, Timmons, Butterworth, & Lugas, 2012; Taylor & Mailick, 2014), postsecondary education (Migliore et al., 2012), and receipt of services (Chiang et al., 2013; Esbensen et al., 2010; Liptak et al., 2011; Migliore et al., 2012; Orsmond et al., 2004). Three key categories of predictors were central to the hypothesis in the current study: functional performance, family background, and parent expectations.

Functional performance. By far the most commonly studied predictors, the functioning level of individuals with ASD has repeatedly been shown to predict adult outcome. Specifically, functioning of individuals with ASD related to cognition, language/communication skills, diagnostic severity, and self-care skills have been found to predict to employment, residential independence, and social participation. Review publications have often cited cognition/IQ as the most common and important predictor of outcomes (Levy & Perry, 2011; Seltzer, Shattuck, Abbeduto, & Greenberg, 2004). Increases in IQ, as well as the lack of a co-morbid intellectual disability diagnosis, have been found to positively predict employment outcomes (Chiang et al., 2013; Howlin et al., 2004; Liptak et al., 2011), friendships (Howlin et al., 2004), daily living independence (Gillespie-Lynch et al., 2012), and overall outcomes (Farley et al., 2009; Howlin et al., 2013). However, Howlin and colleagues (2004) suggested that there may be a maximum IQ (i.e., 100) for which this relationship holds, and Gillespie-Lynch and colleagues (2012) suggested that malleability of cognitive status may be more relevant than early scores. Similarly, greater language, communication, or social skills have been associated with positive outcomes related to employment (Liptak et al., 2011; Roux et al., 2013), friendships (Liptak et al., 2011; Orsmond et al., 2013; Orsmond et al., 2004), daily living independence (Gillespie-Lynch et al., 2012), and overall outcomes (Gillespie-Lynch et al., 2012; Howlin et al., 2013; Howlin et al.,

2000). Autism severity has also been identified as a predictor of overall outcome (Eaves & Ho, 2008; Howlin et al., 2013). Finally, greater self-care skills have been suggested to positively predict employment (Roux et al., 2013), friendships (Liptak et al., 2011), and overall outcome (Esbensen et al., 2010) for adults with ASD.

Family background. Though inconsistent, family background variables such as race, parent education, and household income have been identified to predict outcomes of adults with ASD and other developmental disabilities. Studies have shown race can predict differential outcomes of youth with ASD (e.g., black youth have more negative social outcomes and white youth more residential independence; Liptak et al., 2011). Additionally, parent education is suggested to have an influence on social participation (Liptak et al. 2011) and household income on employment of adults with ASD (Chiang et al., 2013; Liptak et al., 2011; Roux et al., 2013). Household income has also been suggested to be related to career decision making among youth with disabilities (Lindstrom, Doren, Metheny, Johnson, & Zane, 2007). Furthermore, it is well-documented in child development literature that family background variables can predict children's functional performance (e.g., McLoyd, 1998); thus, given the consistent findings between functional performance and outcomes described in the previous section, family background variables should be given consideration as factors related to adult outcomes.

Parent expectations. Research and theory suggest that expectations can have a profound influence on how things unfold (Eccles & Wigfield, 2002) and that parent expectations contribute to family decision-making about the future (Hogan & Astone, 1986; Lindstrom et al., 2007). Using data from the National Longitudinal Transition Study-2 (NLTS2), Doren, Gau, and Lindstrom (2012) identified parent expectations of future employment (i.e., paid job: definitely will, probably will, probably will not, definitely will not) as a significant predictor of

later employment for youth combined across multiple disability categories and Carter and colleagues (2012) had similar findings specific to youth with severe disabilities. Parent expectations of future employment were also found to significantly differentiate individuals with ASD who were later employed versus unemployed; however, this variable was not significant when in a multivariate logistic regression model (Chiang et al., 2013). Parent expectations variables, though commonly explored as independent predictors, have been shown to be related to both family background variables (e.g., income level; Doren et al., 2012) and disability groups (with inherent functional performance differences; Blacher et al., 2010; Doren et al., 2012; Grigal & Neubert, 2004). Since family background and functional performance variables have also been frequently cited to predict outcomes for adults with ASD, the current study aimed to test parent expectations as a mediator of these relationships. Maintaining a focus on individuals with ASD was important in this study because extant research suggests that parent expectations differ by disability type (Blacher, Kraemer & Howell, 2010; Doren et al., 2012; Grigal & Neubert, 2004), that they may function differently across different disability groups (Doren et al., 2012), and that parents of youth with ASD are reported to have some of the least ambitious expectations for their children's futures (Newman et al., 2011), which is assumed to be related to unique aspects of the diagnosis.

Study purpose. The complexity of predicting outcomes of adults with ASD is evident throughout the literature and the field could benefit from increased clarity of what broad factors influence outcomes in a consistent and generalizable way. The intention of the present study was to, first, extend previous work by utilizing existing empirical evidence on relationships between individual variables and incorporating the use of latent variables to explore relationships among broader constructs. Furthermore, parent expectations was tested as a mediator of outcomes,

rather than as an independent predictor; this approach was hypothesized to be a more accurate portrayal of the role of expectations on outcomes and allowed for examination of both direct and indirect influences on young adult outcomes in ASD. Two main research aims are explored in this study: (1) Confirm predictive relationships from family background and functional performance variables to young adult outcomes using latent variable modeling; and (2) Test the hypothesis that parent expectations function as a significant mediator of the predictive relationships from family background and functional performance to young adult outcomes. Addressing these aims holds potential to expand current understanding of the role of parent expectations on the outcomes of adults with ASD which may be a factor malleable through intervention.

4.2 Methods

NLTS2 dataset. The National Longitudinal Transition Study-2 (NLTS2; IES, n.d.) involved five data collection waves over 10 years on a nationally-representative cohort of students enrolled in special education services in the U.S. when the study began in 2000. Sampling occurred through a multi-stage process in which school districts were selected at random based on geography, size, and demographic characteristics, and then students enrolled in special education were randomly selected based on age and disability classification (IES, n.d.). The project was funded by the U.S. Department of Education with data collection beginning when youth were ages 13-16 and concluding when they were 21-25 years of age (IES, n.d.). The NLTS2 sample totaled over 11,000 youth from throughout the country and included data collected from parents, youth, and schools. The authors of the present analysis were granted access to this dataset through an Institute of Education Sciences (IES) Restricted-Use Dataset Agreement, and the project was approved by the university's institutional review board. In

accordance with the data-use agreement, data were stored and analyzed in a secure room on a non-networked computer and all reported sample sizes and percentages are rounded to the nearest 10.

Sample. The present analysis included only individuals from the dataset who at the first wave had a district-provided primary disability classification of autism and/or parent confirmation of an autism diagnosis ($n=1170$), and involved using wave one variables to predict to wave five outcomes. All 1170 cases were included in the portions of the models for which their data were available; however, about 400 individuals in this group were lost to follow-up by the fifth/final wave and that group significantly differed from those with wave five data on race/ethnicity ($\chi^2=17.7, p<0.001$), household income ($\chi^2=41.5, p<0.001$), and mother's education ($\chi^2=30.4, p<0.001$) from wave one, with the group lost to follow-up most likely to be non-white and from families with less household income and lower levels of mother's education. Those included at wave five versus those lost to follow-up did not significantly differ by age, gender, academic performance, self-care skills, social skills, or parent expectations at wave one (all $ps>0.20$).

Variables. From the NLTS2 database, variables were selected which aligned with the hypothesized model and were maximally complete for the available sample (<20% missing). For the purposes of the current analysis, variables available in the NLTS2 database were re-coded as needed to align with the hypothesized model and to improve distribution normality. Table 5.1 displays descriptions of the included variables and their distribution in the sample. Four latent variables were created for the purposes of the present analysis: (1) *family background* included race/ethnicity (white/non-Hispanic versus other), household income, and mother's education; (2) *functional level* included academic performance, social skills, and self-care skills; (3) *parent*

TABLE 4.1: Study Variables

Variable	Sample Distribution[†]	Data source
Age in years—Mean (SD)	14.7 (1.2)	wave 1 (school district)
Male gender	80%	wave 1 (school district)
Race/ethnicity		wave 1 (school district, supplemented with parent survey)
White/non-Hispanic	60%	
African American	20%	
Hispanic	10%	
Asian or Pacific Islander	<10%	
Other or multiple	<10%	
Household income		wave 1 (parent survey)
≤\$25,000	20%	
\$25,001 – 50,000	20%	
> \$50,000	40%	
Mother's education		wave 1 (parent survey)
High school or less	30%	
Some post-secondary education	30%	
Bachelor's degree or higher	30%	
High school academic performance		wave 1 (teacher survey, supplemented with parent survey)
Failing (e.g., Ds & Fs)	10%	
Below average (e.g., Cs & Ds)	20%	
Average (e.g., Bs & Cs)	20%	
Above average (e.g., As & Bs)	30%	
Self-Care Skills [8 point scale]		wave 1 (parent survey)
1-5 points	10%	
6 points	10%	
7 points	20%	
8 points (high)	50%	
Social Skills [20 point scale]—Mean (SD)	10.1 (3.5)	wave 1 (parent survey)
Parent expects youth will have paid job in the future		wave 1 (parent survey)
Definitely will not	10%	
Probably will not	10%	
Probably will	30%	
Definitely will	40%	
Parent expects youth will live independently in the future		wave 1 (parent survey)
Definitely will not	30%	
Probably will not	20%	
Probably will	20%	
Definitely will	10%	
Paid work outcome		wave 5 (parent survey)
No current or past paid employment	50%	
Past employment, none current	10%	
≤20 hours of current employment	20%	

>20 hours of current employment	10%	
Independent living outcome		wave 5 (parent survey)
Does not live independently	90%	
Lives independently	<10%	
Social participation outcome		wave 5 (parent survey)
Never gets together with friends	40%	
Gets together with friends once per week or less	30%	
Gets together with friends two or more times per week	20%	

Notes. [†], percentages are rounded to the nearest 10 in accordance with the data use agreement with the Institute for Education Sciences (IES). Percentages for wave one variables are based on the full sample ($n=1170$) and for wave five variables on the sample with successful follow-up ($n=770$).

expectations included expectation that youth will have a paid job in the future and expectation that youth will live independently in the future; and (4) *young adult outcome* included employment, residential independence, and social participation. Gender and age were included in the models as covariates to account for potential related variations that have been previously reported (e.g., Chiang et al., 2013; Liptak et al., 2011; Orsmond et al., 2004; Roux et al., 2013; Taylor & Mailick, 2014).

Data analysis. Data management and descriptive analyses were conducted using the Statistical Package for Social Sciences, Version 22 (SPSS; IBM, 2013) and modeling was conducted using Mplus, Version 7 (Muthén & Muthén, 2012). Structural equation modeling techniques were used in this analysis to test a hypothesized model using mediation to measure both direct and indirect relationships (Bowen & Guo, 2012; Kline, 2011). The size of the available sample was sufficient to run the hypothesized models (Kelloway, 2015; Kline, 2011). The models were estimated using a weighted least squares estimator with a diagonal weight matrix (i.e., WLSMV in Mplus), which is recommended for models including categorical, dichotomous, and continuous variables (Muthén, 1984). Indicator parameters were freed and

latent variables were standardized (variances fixed to one and means to zero) to produce more consistent and correct estimates (Kline, 2011). The WLSMV estimator addresses missingness using pairwise present data, which allows for use of all available correlations (Muthén & Muthén, 2012).

Two structural equation models were fit to align with the two research aims. The first, addressing aim 1 (i.e., *confirm predictive relationships from family background and functional performance variables to young adult outcomes using latent variable modeling*), tested the base model which excluded parent expectations. This was run as a preliminary step to explore relationships among latent variables and confirm consistency with extant literature. The second addressed aim 2 (i.e., *test the hypothesis that parent expectations function as a significant mediator of the predictive relationships from family background and functional performance to young adult outcomes*), which incorporated parent expectations and tested the primary hypothesis that parent expectations would significantly mediate the relationships to adult outcomes. Both models included age and gender as covariates for all endogenous variables.

Appropriateness of model fit was assessed using multiple fit indices: Chi-Square Test of Model Fit (χ^2), Comparative Fit Index (CFI), Tucker Lewis Index (TLI), and Root Mean Square Error of Approximation (RMSEA). Chi-square parameter and significance were considered; however, a significant (undesirable) χ^2 statistic is common with sample sizes above 200 (Kelloway, 2015; Kline, 2011). In large sample sizes, a ratio less than 2 or 3 of the statistic to its degrees of freedom (*df*) can provide an alternate estimate of acceptability of model fit (i.e., normed chi-square; Schreiber, Nora, Stage, Barlow, & King, 2006; Tabachnick & Fidell, 2013). CFI and TLI values >0.95 and RMSEA values of <0.05 or <0.06 are considered to indicate good

fit (Kelloway, 2015; Tabachnick & Fidell, 2013). Model trimming and respecification were considered (Kelloway, 2015; Kline, 2011), but no adjustments were deemed necessary.

4.3 Results

Figure 4.1 displays the first model (Model 1), which was run as a preliminary step toward testing the primary hypothesis (Model 2). Model 1 demonstrated adequate overall model fit [$\chi^2(38)=88.37, p<0.001$, ratio=2.3; RMSEA=0.034 (90% CI: 0.025 - 0.043); CFI=0.95; TLI=0.92] and justified the use of latent variables to model the relationships of interest. Furthermore, as expected, significant direct pathways were confirmed from family background to functional performance and young adult outcome, and from functional performance to young adult outcome. Thus, the model demonstrates the effective use of the created latent variables to confirm relationships identified in previous literature. Regarding the covariates, age did not significantly predict functional performance or young adult outcome, and gender only had a significant direct relationship to functional performance (male gender related to improved performance; $\beta=0.14, p<0.001$) and not to young adult outcome. Table 4.2 lists the unstandardized estimates and standard errors for all tested pathways, including direct, total, and indirect effects in both models.

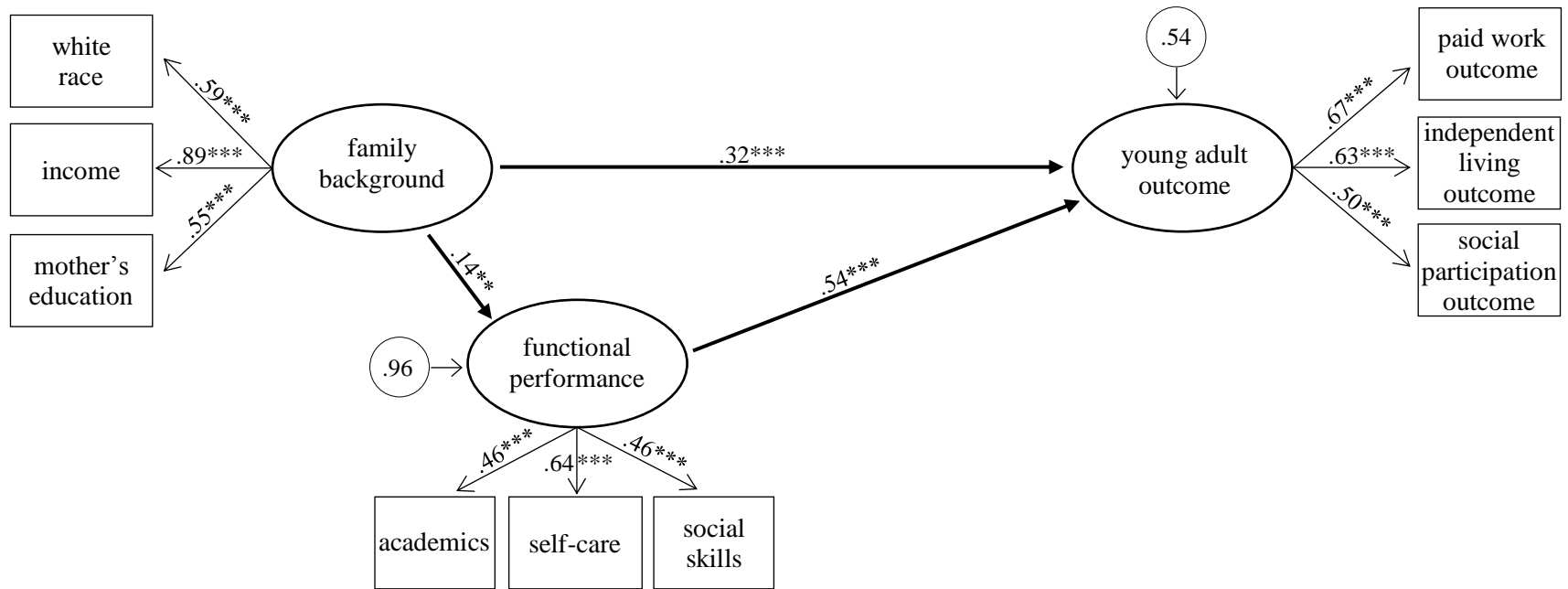
Figure 4.2 displays Model 2—the full model testing the primary hypothesis—which demonstrated good fit with the data [$\chi^2(54)=134.96, p<0.001$, ratio=2.5; RMSEA=0.036 (90% CI: 0.028 - 0.043); CFI=0.97; TLI=0.95]. Model 2 reveals parent expectations was the only included variable with a significant direct pathway to young adult outcome. In contrast to the relationships seen in Model 1, with parent expectations added, pathways from family background and functional performance to young adult outcome are no longer significant. Rather, the model supports the hypothesis by identifying parent expectations as a significant mediator of the

**TABLE 4.2: Unstandardized Estimates and Standard Errors
of Direct, Total, and Indirect Effects**

	Model 1		Model 2	
	<i>B</i>	<i>SE</i>	<i>B</i>	<i>SE</i>
<i>Direct</i> → functional performance				
family background	0.15**	0.06	0.14*	0.06
age	0.06	0.04	0.06	0.04
male gender	0.37***	0.11	0.37***	0.11
<i>Direct</i> → parent expectations				
family background	—	—	0.54***	0.12
functional performance	—	—	1.54***	0.27
age	—	—	-0.07	0.06
male gender	—	—	0.24	0.18
<i>Direct</i> → young adult outcome (Out)				
family background (FB)	0.44***	0.11	0.16	0.18
functional performance (FP)	0.72***	0.15	-0.37	0.50
parent expectations (PE)	—	—	0.86**	0.32
age	0.07	0.06	0.15	0.09
male gender	0.21	0.20	0.10	0.27
<i>Total</i> FB → parent expectations	—	—	0.75***	0.14
<i>Indirect</i> FB → FP → PE	—	—	0.22*	0.09
<i>Total</i> age → parent expectations	—	—	0.01	0.06
<i>Indirect</i> age → FP → PE	—	—	0.09	0.06
<i>Total</i> gender → parent expectations	—	—	0.81***	0.22
<i>Indirect</i> gender → FP → PE	—	—	0.57**	0.20
<i>Total</i> FB → young adult outcome	0.54***	0.12	0.75***	0.20
<i>Indirect</i> FB → Out	0.11*	0.04	0.59**	0.22
FB → FP → Out	0.11*	0.04	-0.05	0.07
FB → FP → PE → Out	—	—	0.18	0.11
FB → PE → Out	—	—	0.46*	0.20
<i>Total</i> FP → young adult outcome	—	—	0.95***	0.21
<i>Indirect</i> FP → PE → Out	—	—	1.32*	0.57
<i>Total</i> age → young adult outcome	0.11	0.06	0.14	0.09
<i>Indirect</i> age → Out	0.04	0.03	-0.01	0.05
age → FP → Out	0.04	0.03	-0.02	0.03
age → FP → PE → Out	—	—	0.07	0.06
age → PE → Out	—	—	-0.06	0.06
<i>Total</i> gender → young adult outcome	0.48*	0.21	0.65*	0.30
<i>Indirect</i> gender → Out	0.26**	0.10	0.55**	0.20
gender → FP → Out	0.26**	0.10	-0.14	0.19
gender → FP → PE → Out	—	—	0.49*	0.25
gender → PE → Out	—	—	0.20	0.17

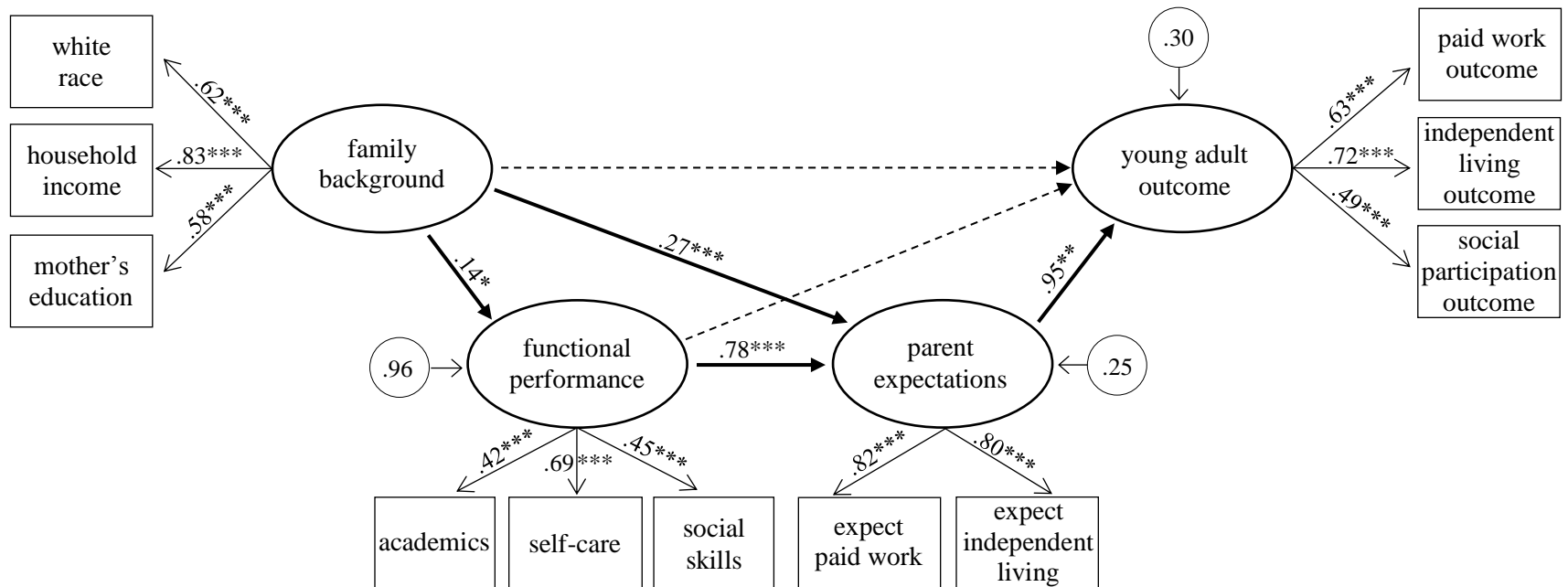
Notes. —, pathway not tested in model. *, $p \leq 0.05$; **, $p \leq 0.01$; ***, $p \leq 0.001$.

FIGURE 4.1: Model 1: Preliminary Structural Equation Model without Parent Expectations



Notes. Standardized estimates are listed for significant paths in the model. Direct paths were included from covariates (age & gender) to all endogenous variables in the model but are not shown. *, $p \leq 0.05$; **, $p \leq 0.01$; ***, $p \leq 0.001$. Model fit: $\chi^2(38) = 88.37^{***}$, ratio = 2.3; RMSEA = 0.034 (90% CI: 0.025 - 0.043); CFI = 0.95; TLI = 0.92.

FIGURE 4.2: Model 2: Full Structural Equation Model



Notes. Standardized estimates are listed for significant paths and dashed arrows represent nonsignificant paths. Direct paths were included from covariates (age & gender) to all endogenous variables in the model but are not shown. *, $p \leq 0.05$; **, $p \leq 0.01$; ***, $p \leq 0.001$. Model fit: $\chi^2(54) = 134.96$ ***, ratio=2.5; RMSEA=0.036 (90% CI: 0.028 - 0.043); CFI=0.97; TLI=0.95.

relationships from family background and functional performance to young adult outcome. The direct relationship from family background to functional performance persisted. This model also tests predictors of parent expectations; significant direct relationships were identified from both family background and functional performance to parent expectations. The significant covariate relationships were consistent from Model 1 to Model 2, despite the addition of parent expectations; the only significant direct covariate relationship was from gender to functional performance ($\beta=0.14, p<0.001$). Age did not significantly predict functional performance, parent expectations, or young adult outcome, and gender did not significantly predict parent expectations or young adult outcome. A significant total indirect effect of gender to young adult outcomes was identified (significant specific indirect effect through functional performance via parent expectations) and from gender to parent expectations through functional performance.

4.4 Discussion

In the present analysis, structural equation modeling was used to test parent expectations as a mediator of outcomes for young adults with ASD. Without the inclusion of parent expectations (i.e., Model 1), both family background and functional performance were significant and direct predictors of young adult outcome. However, in Model 2, these effects were found to be significantly mediated through parent expectations and lost their significant direct prediction to outcomes. These analyses complement and extend previous literature on outcomes of adults with ASD in three key ways: (1) by providing evidence for the feasible application of latent variables to models predicting outcomes; (2) by identifying cross-sectional predictors of parent expectations; and (3) by expanding understanding of the role of parent expectations in longitudinal prediction of outcomes.

The majority of the extant literature exploring outcomes of young adults with ASD has taken one of two broad approaches to outcome measurement, either using an overall outcome rating or focusing on prediction to singular variables (Henninger & Taylor, 2013). Singular variables or composite scores have also most commonly been used as predictors of outcomes. The present project involved testing the use of four latent variables (i.e., family background, functional performance, parent expectations, young adult outcome) to fit models predicting young adult outcome; the variables demonstrated appropriate measurement fit and utility in the models. A benefit of using a latent variable approach is the acknowledgement that the theoretical construct of interest is not entirely observable; observable indicators are utilized but measurement error is taken into consideration in the analysis (Kline, 2011). Although limited in this study by the variables available in the NLTS2 dataset, this approach offers vast possibilities for exploration of more complex theorized relationships among constructs in future research.

In addition to interest in predicting young adult outcomes, this project allowed testing the extent to which family background and functional performance variables predicted parent expectations. Previous research has explored parent expectations as a predictor of outcomes (Carter et al., 2012; Chiang et al., 2013; Doren et al., 2012) and influences on parent expectations including family background variables (Doren et al., 2012) as well as diagnostic group (Blacher et al., 2010; Grigal & Neubert, 2004). The present analysis provided evidence that both family background (e.g., race/ethnicity, household income, mother's education) and the youths' functional performance (e.g., academics, self-care skills, and social skills) significantly and directly predict what parents expect for their children's futures (e.g., if they will get a paid job and live independently). Understanding the roles that both youth- and family-level variables play in the development of parent expectations can provide context for professionals working

with parents to help them prepare for the future. However, additional work is warranted to uncover more about what contributes to the development of parent expectations; both qualitative and quantitative approaches could enhance what is currently known and further inform clinical practice with youth with ASD and their families.

Most notably, the current analysis confirmed the primary hypothesis that parent expectations mediate the relationships from family background and functional performance to young adult outcomes. In fact, when added to the model, parent expectations was the only variable with a significant direct relationship with outcome. This extends previous literature that has emphasized the importance of youth functioning (e.g., cognitive status, language skills) and, to a lesser extent, family background in predicting longitudinal outcomes (e.g., Levy & Perry, 2011; Liptak et al., 2011; Seltzer et al., 2004). Additionally, studies have previously looked at parent expectations only as a predictor of outcomes (e.g., Doren et al., 2012) without considering what may have influenced the outcomes. Altering their perception from a predictor (i.e., an independent belief parents may hold) to a mediator (i.e., influenced by family and youth characteristics) should help practitioners and researchers to better understand, account for, and address parent expectations.

There do, however, remain unanswered questions about parent expectations. For example, an important question for consideration is whether or not parent expectations are malleable factors and if adjustment of expectations could have a positive influence on outcomes. It is assumed that parents' expectations play an important role in decision making about the future (Lindstrom et al., 2007); thus, once expectations are in place, options and experiences may be limited as a result of decisions that have been made. If that is the case, explicitly addressing parent expectations through education, counseling, or coaching methods during transition

planning could result in more available opportunities for youths. However, it is also reasonable to consider alternately that the strong relationship from expectations to outcomes may be related to a nuanced understanding parents have about their child's future potential and that these are their 'realistic' expectations, which Kraemer and Blacher (2001) found were significantly different and less ambitious than their 'ideal' expectations for the future of their children. In this case, it is unlikely that working with parents to try to adjust their expectations would make a meaningful difference. Considering the complexity of the transition planning process, it seems that attempting to change parent expectations on their own—if that were even feasible—would have a limited impact. However, addressing parent expectations (and youth's expectations for self) in conjunction with other interventions (e.g., skill building or practical experiences) may be a direction worth pursuit.

The relationships between the covariates (age & gender) and model variables also warrant discussion. Gender has been inconsistently identified as related to outcomes in previous studies (Billstedt, Gillberg, & Gillberg, 2005; Chiang et al., 2013; Liptak et al., 2011; Seltzer et al., 2004; Taylor & Mailick, 2014). In the models tested in the current analysis, gender only had a significant direct pathway to functional performance, with male gender related to increased performance. In Model 1, gender had a significant indirect relationship to outcome through functional performance and, in Model 2, through functional performance via parent expectations to outcome. National monitoring sites report higher proportions of intellectual disability diagnoses among females with ASD than males (CDC, 2014), which may contribute to explaining the current finding of increased functional performance in males. Since previous studies did not explore the differential predictions of gender to functional variables versus outcome variables, early functional differences by gender may account for some of the

differences in outcomes in previous studies. This should be explored more closely in future studies. Age did not significantly predict any of the variables in the current models. This contrasts some work that has suggested employment may increase (Shattuck et al., 2012) or decrease (Taylor & Mailick, 2014) with age in adulthood.

Limitations and future directions. The primary limitations in this study are related to the constraints of the NLTS2 dataset. First, the NLTS2 was a descriptive longitudinal study but was not experimental, thus, it cannot prove causality. However, by tracking a cohort of individuals across a 10 year period, causal relationships can begin to be inferred using structural equation modeling techniques (Kline, 2011). Second, the variables available in the dataset limited the development of hypothesized latent constructs and prediction models (e.g., academic performance was used because IQ was unavailable). Furthermore, how parent expectations were defined and measured was constrained by the study design. Finally, there was a substantial portion of the sample (34%) lost to follow-up by the final wave of data collection and this group differed on family background variables which may slightly limit the generalizability of the findings to the full sample. However, despite the limitations of using the NLTS2 dataset, there are substantial benefits this dataset afforded (i.e., access to a large, diverse, and widely representative sample spanning ten years of data collection) that would be otherwise unattainable.

The focus in the current paper was individuals with ASD, whose young adult outcomes and parent expectations are reported to be distinct and more limited than those with other diagnoses. However, the hypothesized model explored in the current study could be expanded to include other diagnoses to both test if parent expectations mediate outcomes within other groups and discover if the processes differ as a function of group. Furthermore, as described above,

there is a need for expanded understanding of what influences parents' expectations as well as if their expectations are malleable. Future work should investigate the extent to which improvements in outcome can be made using education, counseling, or coaching approaches with parents to adjust their expectations, both in isolation and in conjunction with skills-based interventions with the youth with ASD.

4.5 Conclusions

The present analysis involved testing and confirmation of the hypothesis that parent expectations mediate the relationship from family background and functional performance to young adult outcome in individuals with ASD. Using structural equation modeling, this project also demonstrated the utility of latent variables to measure complex relationships among broad constructs related to outcomes of adults with ASD and identified factors that significantly predict parent expectations and young adult outcomes. These findings add context to previous studies examining the role of parent expectations on young adult outcomes and inform potential directions for family-centered interventions and future research.

CHAPTER 5: *LIVING WITH UNCERTAINTY*: HOW MOTHERS OF ADOLESCENTS WITH AUTISM SPECTRUM DISORDER FORM EXPECTATIONS AND PLAN FOR ADULTHOOD

5.1 Introduction

The present study reports on a qualitative exploration of how parents of adolescents with autism spectrum disorder (ASD) form expectations and make plans for their children's adult futures. Research and theory suggest that expectations can have a real and profound influence on how events actually unfold (Eccles & Wigfield, 2002). Thus, knowledge of parent expectations and planning in adolescence is relevant for understanding factors that influence the outcomes of adults with ASD. In a national study, parent expectations of adult outcomes for their adolescent children with ASD were strikingly low compared with those of parents of youth with other disabilities (Newman, 2005). However, little is known about *how* parents of youth with ASD form their expectations for the future. With current research suggesting generally poor—though highly variable—outcomes for adults with ASD (Levy & Perry, 2011), there is a strong need to understand aspects underlying parent expectations and decision-making for the future.

Adult outcomes for individuals with ASD. Individuals with ASD experience social and communication challenges as well as restricted and repetitive behaviors that may persist across the lifespan (APA, 2013; IACC, 2011; Levy & Perry, 2011; Seltzer, Shattuck, Abbeduto, & Greenberg, 2004). Outcomes of adults with ASD are often described as poor (even when compared to other disability groups) despite wide ranges of intellectual functioning among those with the diagnosis; limitations are reported in terms of employment, participation in post-

secondary education, social life, and independence in daily living activities (e.g., Cimer & Cowan, 2009; Hendricks & Wehman, 2009; Levy & Perry, 2011; Seltzer et al., 2004; Shattuck, Orsmond, Wagner, & Cooper, 2011). Adult outcomes of individuals with ASD can have an impact on the health and well-being of the individuals and their families, as well as an impact on their communities (Taylor, 2009).

Extant literature continually suggests that individuals with ASD typically struggle to find and maintain employment (Carter, Austin, & Trainor, 2012; Hendricks & Wehman, 2009; Holwerda et al., 2012; Shattuck et al., 2012) and may only work in segregated settings (Carter et al., 2012), at menial jobs (Taylor & Seltzer, 2011), or for low hours and wages (Cimer & Cowan, 2009; Taylor & Seltzer, 2011). Rates of high school graduation with a diploma are reported to be low (Hendricks & Wehman, 2009) and participation in postsecondary education is relatively uncommon considering the wide range of IQ levels among individuals with ASD (Eaves & Ho, 2008). Social participation is also limited for adults with ASD; many are reported to have no friends (Billstedt, Gillberg, & Gillberg, 2011; Liptak, Kennedy, & Dosa, 2011), limited social interaction (Orsmond, Shattuck, Cooper, Sterzing, & Anderson, 2013), and minimal participation in group activities (Shattuck et al., 2011). Finally, the majority of adults with ASD are reported to live in supportive settings—often, with their parents (Farley et al., 2009; Taylor & Seltzer, 2011) who may experience stress related to caregiving (Cadman et al., 2012; Orsmond, Seltzer, Greenberg, & Krauss, 2006). Taylor (*née Lounds*) and colleagues have emphasized the importance of considering families from a life course perspective (Elder, 1994) when discussing the transition to adulthood, because family members have “linked lives” (Lounds, Seltzer, Greenberg, & Shattuck, 2007) and influence each other in a bidirectional manner (Taylor, 2009).

Parent expectations and planning for the future. Parents of youth with disabilities play an important role in planning for their children's futures, and must wrestle with supports and constraints in order to make transition decisions during adolescence (Ankeny, Wilkins, & Spain, 2009; Kraemer & Blacher, 2001; Lindstrom, Doren, Metheny, Johnson, & Zane, 2007). During the transition planning process, parents (consciously or unconsciously) form expectations about how their children will function as adults which extant literature suggests may subsequently predict the outcomes of adults with disabilities (Carter et al., 2012; Doren, Gau, & Lindstrom, 2012), and specifically with ASD (Chiang, Cheung, Hickson, Xiang, & Tsai, 2012).

This is an especially salient topic related to parents of youth with ASD because their expectations are reportedly among the lowest of any disability group. Findings of a study about parents of youth with severe learning disabilities suggested that parents of youth with ASD experience more worry and have more restrictive expectations for the future than parents of youth with other diagnoses (e.g., Down's syndrome, cerebral palsy; Blacher, Kraemer, & Howell, 2010). Furthermore, in the National Longitudinal Transition Study-2 (NLTS2), parents' expectations for their youth with ASD were reported to be among the lowest of any disability group (Newman, 2005). Specifically, they were the least likely to indicate their children "definitely" would reach adult accomplishments including getting a driver's license, obtaining paid employment, being financially self-supporting, and living independently (Newman, 2005), suggesting pervasive uncertainty.

Despite evidence to suggest that parent expectations predict future outcomes and that expectations of youth with ASD are among the lowest of any disability group, little is known about what contributes to the expectations parents have about the future or the process by which expectations influence adult outcomes. The current project sought to build a qualitative

understanding of how parents of youth with ASD develop their expectations for the future to deepen existing knowledge about factors influencing adult outcomes.

5.2 Methods

This study, which utilized a qualitative approach to data collection and analysis, was approved by the university institutional review board and followed all data security and informed consent/assent procedures. Recruitment and data collection procedures, described next, included adolescents with ASD and their mothers as participants. Only the mothers' interview data are explicitly included in the present analysis; the adolescent interviews contributed to building additional context for the mothers' interviews, but specific analysis will be explored in a separate manuscript.

Recruitment. For the current project, the goal was to recruit parent and adolescent pairs able to and interested in participating in interviews about planning for adulthood. To meet for inclusion, adolescent participants needed to meet three criteria according to parent report: (1) clinical diagnosis of ASD (or one of its variants, e.g., Asperger's syndrome) from a licensed professional in the community; (2) competency to participate in an spoken interview; and (3) currently enrolled in high school curriculum (any type). Recruitment was pursued via email through a listserv of a community-based, non-profit organization for adolescents and young adults with high functioning ASD. Interested families contacted the primary researcher by email or telephone and the researcher provided additional information about the study and determined if the adolescent met criteria for participation in the study. As a token of appreciation for their participation, families received a \$20 gift card.

TABLE 5.1: Sample Characteristics

Pseudonyms (ages)		Race and Ethnicity [†]	Contextual factors	SRS Autism Severity	Mothers' Future Expectations <i>My son definitely or probably will...</i>
Mother	Son				
Amy (45)	Aaron (14)	White	Home-schooling; Oldest child, has younger sister; two-parent household; \$\$\$	severe	get a paid job, live away with supervision, and participate socially
Nancy (52)	Nick (15)	White	Oldest child, has younger brother; parents separated; \$\$	mild-moderate	earn enough money to support himself, live away without supervision, and participate socially
Mary (60)	Mark (16)	Black (adoptive parents are white)	Adopted; has older & younger siblings; two-parent household; \$\$	severe	get a paid job, live away with supervision, and participate socially
Christine (51)	Charles (17)	Black	Only child; father is deceased; \$\$	severe	attend post-secondary school, get a paid job, and live away without supervision
Lori (50)	Luke (17)	White	Youngest child, has older sister; parents separated; \$	mild-moderate	attend post-secondary school, earn enough money to support himself, live away without supervision, and participate socially
Judy (39)	Jamal (17)	Black	Oldest child, has younger brother; two-parent household; \$	mild-moderate	attend post-secondary school, get a paid job, live away with supervision, and participate socially
Gabby (52)	George (17)	White	Only child; two-parent household; \$\$\$	mild-moderate	get a paid job, live away from home without supervision

Notes. Household yearly income: \$=<\$30,000; \$\$=\$30-79,000; \$\$\$=>\$79,000. [†]Data on ethnicity were collected; no families reported Hispanic heritage. SRS=Social Responsiveness Scale (Constantino & Gruber, 2005); t-score interpretation: <60=normal, 60-75=mild-moderate, >75=severe.

Participants. Sixteen parents responded to inquire further about the study; the first ten were briefed on the inclusion criteria and procedures (three later decided they were not interested or unable to participate), and the remaining six were placed on a waiting list for possible inclusion if fewer than five families participated or if more interviews were deemed necessary after initial analysis. Ultimately, seven mothers and their adolescent sons with ASD (ages 14-17) participated in qualitative interviews in their homes. One mother also had a younger daughter with ASD (age 12) who participated in an interview and was discussed during the parent interview, but the sections related to the female participant were excluded from the present analysis because her mother's preoccupation with current behavioral problems precluded in-depth discussion of her transition to adulthood. Descriptive information about the mother and son participants is displayed in Table 4.1, along with pseudonyms. Though primarily recruited by convenience, the sample was relatively diverse in terms of race, family make-up, household income, mother and son ages, school system and type, location of residence (participants were spread across four counties in one U.S. state), level of functioning, and plans for the future. Furthermore, only one of the participants had currently or ever participated in activities with the organization who assisted with recruitment; thus, the participants did not share similar social or educational experiences through that organization.

Procedures. The first author—who had previous experience interviewing children with ASD and their families—conducted face-to-face, semi-structured interviews in the participants' homes. A social constructionist paradigm (Daly, 2007) was used to guide interviews in order to develop an understanding of how the mothers develop expectations for the future. In this paradigm, the sought reality is built through an interaction in which researcher and participant co-construct a mutual understanding of the subject (Gergen & Gergen, 2008; King & Horrocks,

2010; Mishler, 1986). A semi-structured guide was used during interviews (see Appendix A), but allowed for individualization as each interview was a unique socially-constructed experience between the participant and interviewer (Koro-Ljungberg, 2008). Interviews with the mothers lasted between 25 and 72 minutes (106 minutes with the mother discussing her two children with ASD) and addressed their visions for their sons' futures and influences on their expectations. The topic of planning for the future was also raised by all of the participants during the discussion. Interviews were audio-recorded and transcribed verbatim by the first author.

Additional data useful for describing the sample were collected from the mothers via questionnaire (See Appendix B) including demographic information, responses to questions about expectations for their child's future (based on NLTS2 [n.d.] survey questions), and a standardized parent-report assessment of autism symptoms (the Social Responsiveness Scale [SRS; Constantino & Gruber, 2005]). Additionally, field notes written after each visit allowed the interviewer to document observations and important non-verbal aspects of the interviews that could be relevant for analysis. The interviewer received permission to follow-up with the mothers if needed up to two weeks after their interviews to address follow-up questions that arose during transcription. Two mothers were contacted with clarification questions (e.g., "You told me you do not want your son to live with a roommate, can you explain why?"); both responded and addendums were added to their case notes.

Data analysis. The qualitative analysis followed published recommendations (Coffey & Atkinson, 1996; Miles & Huberman, 1994; Rubin & Rubin, 2005; Schwandt, 2007) and utilized a combination of pen-and-paper methods as well as analytic software (ATLAS.ti 6; Friese, 2011) to aid in the analysis. The process began with verbatim transcription of the data (King & Horrocks, 2010), followed by repeated reading of transcripts and case notes, listening to the

audio recordings, and discussion of the data among members of the research team. Next steps involved close reading with memoing in margins, first by case and then within categorical segments across cases (i.e., data segmented in ATLAS.ti once by adult outcome domain—e.g., employment, social life—and a second time into influences or approaches). Open and axial data coding followed using descriptive and flexible codes followed by a dynamic, iterative process of re-coding and grouping codes based on conceptual analysis (Coffey & Atkinson, 1996; Miles & Huberman, 1994; Rubin & Rubin, 2005; Schwandt, 2007). This process resulted in two broad categories of findings: influences on expectations and approaches to planning. Coding was finalized using ATLAS.ti and included three main themes—each with three subthemes—related to influences (i.e., addressing the primary aim) as well as three types of approaches. The overall purpose of the coding process was explanatory (Schwandt, 2007), to explain how the participant mothers develop expectations and plan for their sons' futures. The interpretation process extended beyond coding and theme building, to consider how the themes act within a broader situation; a model was then created to visualize the interplay among findings.

The first author primarily conducted the analysis, taking additional steps to enhance trustworthiness (Brantlinger, Jimenez, Klingner, Pugach, & Richardson, 2005; Lincoln & Guba, 1985; Schwandt, 2007). First, an audit trail was used to document each step of analysis and at regular intervals two internal auditors (GB & NB) reviewed the overall analysis progress and select complete transcripts, discussed emerging findings, and encouraged consideration of alternate interpretations of the data. Additionally, memoing was used throughout the data collection and analysis processes to promote researcher reflexivity. Finally, thick and detailed descriptions, including verbatim participant quotes, are provided in the findings section to the extent possible as evidence of the themes.

5.3 Findings

Influences on expectations and planning. In response to the primary aim of the interviews, three themes emerged from the qualitative analysis—each with three subthemes—which describe influences on expectations of the seven mothers in the study for the future adulthood of their adolescent sons with ASD: (1) characteristics and experiences of the youth; (2) maternal perceptions, beliefs, and emotions; and (3) stereotypes, stories, and society.

Influence 1: Characteristics and experiences of the youth. The most commonly talked about influence on the mothers' expectations for their sons' futures was related to characteristics and experiences of their sons with ASD. In particular, the mothers discussed their sons' interests and preferences, strengths and challenges, and positive and negative past experiences, and how those have shaped their current thinking about the future.

Interests and preferences. All of the sons had activities or topics that they were particularly interested in—wildlife/nature, computers, reading and writing stories, drawing, aviation, and creating comics. Most mothers had ideas about how their son's interests could be turned into a job, because they saw incorporation of the interest as a necessity for success. Amy stated, "if it's something he's interested in, he'll do it." For example, both Aaron and Nick had strong interests in nature and wildlife, leading their mothers to consider possible employment options that could incorporate work with animals. However, for mothers whose sons did not have strong interests, thinking about the future was difficult. For example, Gabby discussed how George had limited interests, and that there was little potential for his interests in video games and comics to translate into paid employment. Mothers also described their sons' interest, motivation, and determination about their futures, as demonstrated by asking questions and talking about topics such as college, moving out, improving their grades, and what they want to

do after high school. The mothers who witnessed this felt strongly that these displays of motivation were a good sign for the future and positively impacted their sons' potential for success.

The mothers also discussed their sons' preferences, and how they may impact the future. Specifically, many of the sons prefer to be alone which mothers saw as limiting their potential for making friends, finding a romantic partner, and even impacting their living arrangements and employability. However, they all indicated that their sons do not want to be alone all of the time, and do seem to enjoy interactions with others. Amy reported, "he does like people, he wouldn't want to live on his own all the time, he does like interaction." The mothers also described their sons' preferences for routine and structure, believing that these preferences could help with maintenance of positive routines in adulthood, but would also make the transition period difficult. Lori stated, "he likes quiet, he likes routine," and explained that he will struggle with moving out of their home.

Strengths and challenges. Every mother discussed her sons' strengths (i.e., things he does well) and challenges (i.e., things he struggles with), and described how these will likely influence the future. Common strengths discussed included rule following, self-awareness, self-care, follow-through, and being polite, kind, and personable. All of the mothers reported in some way that their sons have abilities, potential, and gifts. Gabby described that George "has great, like, customer service skills, you know, he's very personable, and he greets people, and you know, is always willing to help." In fact, many of the mothers described how their sons seem to be more responsible and independent than their peers and siblings. Amy reported, "he's doing more than what a lot of kids his age would be [able] to do." However, despite these areas of strength, the mothers were often not completely confident those strengths would lead to success.

Amy added, “he’s so incredibly capable in some ways, but in other ways so incredibly child-like.”

Although there were numerous strengths identified by the mothers, the challenges were more often at the center of their rationale for their expectations. Many of the discussed challenges related to social interactions and included vulnerability, inappropriate social behaviors (e.g., acting rude), social awkwardness, and not understanding the value of relationships. Additional challenges included rigidity, difficulty with generalization of knowledge, and limited academic or cognitive ability. Three of the mothers mentioned their child’s intelligence quotient (IQ) in different ways when discussing their potential for the future—Amy felt Aaron’s IQ helped her understand his limitations, Christine discussed that Charles’ high IQ often did not translate to real-life situations, and Nancy was frustrated that Nick’s IQ would never reveal his full potential. Finally, depression and anxiety were identified by some mothers as challenges experienced by their sons that lead to serious concerns about the future. For example, Mary and Christine described periods of serious depression that Mark and Charles had experienced, both fearing that these could re-surface especially if they did not consistently take their prescribed medications.

Positive and negative past experiences. To explain why they expected certain things for their sons’ futures, the mothers often referred to their sons’ past experiences. Many described positive experiences participating in work and volunteer opportunities; these experiences served as evidence for the mothers that their sons could find at least some sort of work in the future. George and Mark had regular part-time work, Charles had worked summer jobs in the past, and Nick had participated in assisted work and volunteer experiences. They also described positive experiences participating in community and school-based activities, such as overnight camps,

marching band, boy scouts, Future Farmers of America, Army-ROTC, and Habitat for Humanity, as well as autism-specific groups and activities. Furthermore, mothers described successful experiences participating in daily life activities including staying home alone overnight, taking public transportation or driving, cooking, cleaning, and self-care. Gabby described, “He got a part time job...he’s so confident in so many ways; he can without hesitation...walk into town and go out to eat by himself and order and pay and, you know, no problem.”

The mothers also described negative experiences that led to greater concerns for the future. Reflecting the challenges described in the previous section, their negative experiences primarily involved social interaction—being judged and teased by peers, being taken advantage of, and being rude to people, to describe a few. For example, despite Mark’s successful employment experiences, Mary described concerns about his future because he has previously been taken advantage of by coworkers:

This is an excellent example. He’s supposed to get out of work at 5:00. I went to pick him up at 5:00 [and] there’s five employees sitting there smoking cigarettes and just doing nothing while inside [Mark]’s running around trying to do the best he can do ‘cause there’s still customers inside. And he’s only supposed to be bussing tables and making milkshakes...but next thing you know, he’s flipping burgers and he’s putting in fries, and he hasn’t been trained appropriately...but, these kids are out there, you know, the rest of the staff is out there...and even the managers...take advantage of him.

Some mothers also described previous depressive episodes as areas of concern for their sons’ futures; Christine explained, “He’s just had issues at times when he didn’t go [to school], when he stopped taking his meds, you know. And still issues with...the kids, but it was mainly the meds and he’d get off track and depressed.”

Influence 2: Maternal perceptions, beliefs, and emotions. The second theme evident in the interviews involved the intersection between cognitive and emotional aspects for mothers;

these components seemed to influence what the mothers expected for the future and how they approached planning. This theme includes mothers' perceptions of what their sons need in order to be successful as adults, personal outlook and beliefs, and emotions about the future.

Perception of what their child will need in order to be successful. Mothers in the study often described what they perceived that their child would need; these perceptions had a strong influence on what they expected and believed was possible for the future. The most common expected need was for support, help, guidance, and supervision. Judy explained, "I think I probably still will have to help him, you know guide him [about] what to do and what to say and what to pay." Mothers described the support they anticipated their child needing including academic help, budgeting, and general supervision to ensure their safety. They also discussed the need to build skills (e.g., study skills, life skills, social skills, problem solving skills) and effective routines before being able to successfully transition. When discussing Mark's ability to manage himself as an adult, Mary conjectured, "he might get it after a while, and maybe become routine. I'm hoping; it's not routine yet." Another common expected need was for extra time and extra steps; Lori described, "I could see it taking a little longer for him," and Gabby concurred that George, "tends to do everything a few years behind his peers."

Mothers in the study described that they could see their children being successful as adults if the situation was *just right*—with the perfectly-created job and right people around them. Indeed, the jobs they envisioned were often so specific that they would be extremely hard to find and secure, if not impossible. In light of this, Gabby discussed the possibility of starting a business specifically for George; she explained, "we would do just about anything to get him what he would need to be independent." Regarding finding the right people, some mothers described their sons needing mentors who are able and willing to take the extra time and

attention that they will need in order to be successful. “I got to find somebody...in his field that sees his potential and his gift,” Nancy explained. Christine expects that her son will be able to find the right friends in the future:

It’s a matter of finding you know, quote, ‘your people’ you know, whenever he finds his group of people...they weren’t in high school and he probably doesn’t realize that. A lot of times your people are *not* in high school, you know, you don’t find them there.

Personal outlook and beliefs. Each mother in the study alluded to their personal beliefs and outlooks on life as they explained what they expect for their sons’ futures. For Nancy, her beliefs involved trusting and having faith that everything will work out:

I just have to trust; I have to live in the moment...I have a faith in something, whether you want to call it God or the universe...I believe that if I keep doing the right things for him, that the outcome is going to be, it’s going to be fine. [And] even if it’s not fine, it’s what’s, you know, it’s what’s meant to be and that it’s his life story and not mine.

Amy, however, described how she needed to realign her outlook and focus on reality in order to protect Aaron:

I never liked the idea of predicting that someone’s not going to achieve more than...you know, I always like to think the best, and that they always have these opportunities. But when you’re dealing with a child with autism, such as...[Aaron], you have to be realistic, you can’t just sit there and go, ‘oh, he can do anything.’ People say that to me, ‘oh, he seems fine, he’ll move out’ and whatever. I can’t...I don’t have that luxury. I have to keep him, you know, safe and, and keep things kind of realistic.

Emotions about the future. The mothers in the study repeatedly referred to their own emotions, which seemed to play a role in how they thought about and planned for the future. Mothers discussed their hopes, wishes, and prayers, alongside their fears and worries. Judy repeatedly referred to the “mother’s fear” she felt that seemed to limit her ability to perceive Jamal’s future as successful, despite her acknowledgement of his abilities. She described, “I think he’ll be fine, it’s just, I’m scared.” Nancy explained the connections between her thoughts about the future and her emotions: “I think about the future, [but] I can’t spend a lot of time there

because it could create a lot of emotional upheaval for me, and worry.” Gabby described how she has and will continue to experience intense worry about George’s future: “you know, you can see him accomplish something, you can see him hit this developmental milestone, you can do all this, but that discomfort, or um, worry, or concern about what the future holds, that *never* goes away.”

Despite their intense worries and fears, some mothers described being able to still feel happiness, excitement, pride, and inspiration about what their sons have done and about their futures. Christine explained, “I’m, like, terrified, but if he wants to do it, I’m, you know, I’m happy...I’m always happy when he wants to do something.” When discussing Aaron’s successful participation in a social cooking group, Amy revealed, “so those kinds of things really, really inspire me to see that, hey, he’s really capable of more than maybe what I’m giving him credit for.” Lori concluded her interview stating,

I’m very happy with, with the way things are going with him, very proud of him, very happy. And...you know, it’s, it hasn’t come easy at times, but, you know, I’m glad of the progress he’s made and...I see a bright future for him...I really do.

Influence 3: Stereotypes, stories, and society. The final theme that describes influences on the mothers’ expectations for the future involves influences external to the mothers and sons. This theme encompasses outside influences that contribute to what the mothers expect and are planning for the future, and includes stereotypes, stories of others, and societal/social influences.

Stereotypes. In their interviews, some mothers alluded to stereotypes of people with ASD, of teenagers, and of males. Autism stereotypes were described to limit how others perceived their sons, but also seemed to play a role in how the mothers built their expectations and plans for the future. Nancy, for example, explained, “I know autistic people often times are self-focused, but if that takes over, I worry about him out in the world.” However, for some

mothers, it was difficult to think about their sons' futures because even the stereotypes they know of people with ASD did not fit—their children are different. Gabby explained, “he’s not one of these, um, kids with autism who has this like one area that he’s academically gifted in...like computers or electronics, you know.” Similarly Lori described, “you know, you hear of autistic kids that they’re distanced, [but] he was always more huggy...very attached to me;” she hoped this suggested he could build relationships in the future.

Stereotypes of teenagers—teenage males in particular—also seemed to add confusion about what to expect in the future. The mothers seemed to have difficulty untangling whether observed behaviors were related to the diagnosis of ASD or were typical teenage or male behaviors. As Judy discussed if she believed Jamal could live independently in the future, she stated, “I haven’t seen it, maybe just [because he’s a] teenager, but I haven’t seen it” regarding his ability to manage his daily activities. Male stereotypes had a similar effect; after explaining Mark’s minimal attention to hygiene, Mary considered, “and sometimes it’s just a guy [thing]...my brothers are pigs.”

Stories of others. Mothers described how stories about other people have played a role in their thinking about the future. For Nancy and Nick, reading and hearing stories of people with ASD who are successful—such as Temple Grandin, an author and widely-recognized advocate for individuals with ASD—have been important for their development of plans for the future. Judy described elevating her expectations as a result of attending parent groups and reading success stories on autism websites: “Looking at the autism websites and looking at adults who have made it...who live on their own, so that gives me some encouragement. So, I think he can.” Others were encouraged by stories of people who have succeeded taking less traditional paths. For example, Christine explained that their physician took a non-traditional path through college,

which validated her belief that there is more than one road to success. Some mothers also seemed unsure about the future because of the limited examples they have of people with ASD. Gabby explained, “at least [you] know if you have a typically developing kid [that] most people grow up and do something;” she does not feel there is that same certainty about people with ASD.

Societal/social influences. Other people’s perceptions of their sons seemed to play a role in how the mothers were thinking about and planning for the future. This included both input from individual people in their lives, as well as broader society-level influences. Many mothers described external pressures placed on their sons regarding their futures. Christine explained, “he had pressure from some people like, ‘he needs to go to a 4 year [college],” but she did not feel this was the best path for Charles. Lori also received un-welcome advice from others: “I hear from a lot of moms, ‘you got to cut those strings!’ you know, ‘let him go!’ but, uh, we’ll see how he does in the next few years.” Input from professionals also influenced the mothers’ planning. Judy, Nancy, and Christine reported very positive influences from therapists and counselors. However, Mary described feeling Mark’s future stifled by educational professionals:

They asked him [at his IEP meeting] what he saw his future to be, and he said, ‘um, living in an apartment and, and going to college...’ I said, ‘well, you know, I’m thinking that’s a good goal to shoot for’ and everyone’s looking at me like, ‘do you hear what he’s saying?’ I’m like, ‘yea.’

The mothers also explained that broader systems are not in place to promote the success of their sons. Nancy described that the world is not set-up for people with ASD, which is an external limiter of his potential: “I know he’s capable of so much more, but our world isn’t set up for that yet, and so, he can’t shine the way I think he really could shine.” Lori expressed a need for more “social education and social awareness” about ASD in the community. Finally, Amy explained that schools are not set-up in a way that promotes success for people with ASD: “I

don't mean to pick on the schools, they do what they do, but they haven't really been able to adjust yet to this whole autism thing, especially for the higher functioning kids."

However, despite their reports of general lack of knowledge and acceptance of people with ASD in the community, there was discussion about how the situation has improved somewhat. Nancy noted,

Nowadays, you meet so many people that understand and have family members or friends who have kids with autism, so they get it a little bit more than when he was first diagnosed and I was always getting lots of stares.

Lori also described how she thinks there is more room in today's society for people like Luke: "I think decades ago these people would not integrate into society, whereas now...the geeky-type people are...the way technology has sky-rocketed and that's now a great career...it's more accepted."

Approaches to planning. Although approaches were not directly asked about in the interviews, all of the mothers incorporated discussion of the approaches they are taking to prepare their sons for adulthood into the conversation about their expectations. The mothers described three main approaches to planning: (1) preparing, involving, and encouraging; (2) remaining flexible and ready to make adjustments; and (3) reaching out.

Approach 1: Preparing, involving, and encouraging. All the mothers described preparatory experiences they have been or will be getting their sons involved in so that they can be successful as adults. These experiences included working part-time, volunteering, participating in social groups, and taking on responsibilities at home. The mothers described their plans to guide their sons to as many opportunities as possible and facilitate development of skills for adulthood. Nancy explained her plan to build skills for Nick to live on his own: "every summer between now and when he graduates from high school, we're going to be sending him

away to some kind of experience where he's independent and alone, living, you know, with other people." The mothers also discussed practicing and role-playing to build routines and skills for adult life, such as cooking, cleaning, and other chores, taking care of themselves (e.g., managing their hygiene and staying organized), learning social and life skills, and practicing solving problems.

The mothers often talked about exploring opportunities and options *with* their sons, and involving them and their interests as much as possible. Nancy explained how they work together: "He and I can talk about these things, and we have been doing a lot of that lately, just exploring career thoughts and ideas." Lori explained, "he wants to fly small planes, so...[I'm] helping him kind of, figure out a career that can involve his interest in doing that." Judy described her plan to involve Jamal: "they had a meeting about colleges and people with special needs and what to do, so when that comes up this year, I'm going to take him...so he can listen and know what to do."

Encouraging their sons seemed to also play an important role in mothers' approaches to planning for the future. Mary reported, "I always say to him, 'I believe in you.' I do believe in him; he is intelligent." Lori said, "I'm very proud of him, and I continually tell him that, 'I'm proud of you.'...you know, kids, they need to be encouraged, they need to know they're doing the right thing." Judy reflected on her own experience transitioning to adulthood: "[my parents] were supportive of me, so I think I'll be supportive of him, as much as he'll let me."

The mothers also talked about the substantial effort caring for their sons has been up to this point, and how they will continue to do a great deal of work to guide their sons through the transition to adulthood. Some expressed that they do hope to have some relief and opportunities to live their own lives again. Christine described how she wants Charles to go off and do his

own thing—spread his wings, she said, “and let me spread mine.” Lori light-heartedly cried out, “I don’t want a 45 year old living with me!”

Approach 2: Remaining flexible and ready to make adjustments. Mothers talked extensively about having to remain flexible in their thinking about the future. The phrase, “we’ll see,” was said by every mother at least once, and in total 22 times across interviews; they discussed the need to wait and see how things go, and then adjust as needed. Christine explained that she has not been thinking too far into the future: “it’s just been so much focusing on, just like right now...we’ve just kind of been looking at a lot of, maybe, mid-term goals, instead of long term...just have to see how it goes.” Lori said, “I’m just going to have to play it by ear.” The mothers often talked about their ideal goals as well as their back-up plans; Nancy explained hers: “If he can’t live on his own, I mean, that’s certainly the goal, [but] I would probably...get an apartment on a bus line, and he could then take the bus and commute to work that way.” Christine discussed the extra importance of back-up plans because she is a single mother:

I always feel like I am not going to always be here, and so, I want to make sure if he goes to school and graduates and, you know, fine...It’s not my dream for him to just have [Social Security Disability benefits], you know, but I want a safety net for him, because, he’s by [himself]...we have family, but you know, there’s nobody like your parents.

Approach 3: Reaching out. Mothers discussed various ways that they have been reaching out to the community for resources in order to promote successful transition to adulthood. Reaching out to professional resources was common, which included therapists (e.g., psychologists, counselors), job counselors, vocational rehabilitation, clinics, and physicians. Physicians were primarily discussed in their role of prescribing medications that help their sons to function better. Mothers also discussed accessing courses available through school, church programs, and ASD-specific community groups that have played a role in preparation for adulthood. Finally, the mothers discussed keeping tabs on available resources and were

constantly on the look-out for new developments; all of the mothers noted the lack of resources for adolescents and adults with ASD.

Connecting to other parents of children with ASD was another primary way that mothers were reaching out to plan for adulthood. This included parent-support groups as well as informal relationships based on shared experiences. Additionally, the mothers described working to connect their sons to other youth with ASD, or peers who were similar to them in some way. In general, the mothers seemed to feel that relationships with other youth with ASD, or who were ASD-like, would be most realistic for their sons, though they often struggled to connect them.

Lori explained:

[There were] three boys that all had similar issues, and we tried getting them to inter[act], and they would naturally gravitate to each other if they were in class, but to do that outside of class, it's hard to get them [together].

Despite experienced difficulties, mothers expressed hope that their sons would be able to connect with others like them in the future.

5.4 Discussion

This study was a qualitative exploration of how mothers of adolescents with autism spectrum disorder (ASD) form expectations for their children's adult futures. Research consistently demonstrates poor, yet variable, outcomes for adults with ASD in multiple domains of adult functioning, including employment, social participation, and daily living activities (Levy & Perry, 2011). The seven mothers in this study expressed grave uncertainties about their sons' futures, with concerns across these adult domains. Using an explanatory process to analyze interviews collected based on a social constructionist paradigm, three primary themes were identified which describe influences on the mothers' expectations: youth characteristics and experiences; maternal perceptions, beliefs, and emotions; and stereotypes, stories, and society. Additionally, though not expressly asked, the mothers all integrated discussion about their

approaches to planning, which were summarized into three main types of approaches. This discussion has two overarching points: (1) how the specific findings add depth to existing knowledge about influences on parent expectations and future planning for youth with ASD; and (2) how the findings work together as part of a broader situation, emphasizing the interconnected nature of influences, expectations, and approaches to planning during the transition to adulthood.

Integration of findings with existing knowledge. The first theme, which described the mothers' consideration of aspects of their sons' interests, preferences, strengths, challenges, and experiences, was not surprising. They each described considering what their son enjoys and is good at, along with what he struggles with and does not like to do, as they formed expectations for the future, while also maintaining ambitions to change some of the more negative factors (e.g., build skills where they are lacking). The mothers also constructed expectations of how their sons would fare in the future by considering how they had handled and been treated in past experiences. This theme aligns with common recommendations for addressing the needs of youth with ASD (i.e., ensuring their educational instruction is relevant to them and their futures; Test, Smith, & Carter, 2014); in fact, it bears striking resemblance to the federal mandate on transition services, which states that transition plans for students with disabilities should be, “based on the individual child’s needs, taking into account [their] strengths, preferences, and interests” (IDEA, 2004, [34 CFR 300.43 (a)] [20 U.S.C. 1401(34)]).

Notably, however, the expectations of the mothers in the study were not entirely influenced by factors related to their sons. Previous research has emphasized the relationships between the functional skills (e.g., IQ, communication skills) and adult outcomes (Howlin & Moss, 2012; Seltzer et al., 2004). Yet, the second and third themes emphasize factors that influence mothers' expectations for the future but are somewhat external—yet related—to the

youth with ASD. The second, summarizing the intersection of mothers' cognitive and emotional processes, described maternal perceptions, beliefs, and emotions, which had clear influences on their approaches to planning and expectations for the future. In this theme, mothers described wrestling with uncertainties and fears about the future, maintaining hopes, and trying to understand and stay aligned with their own beliefs. Many mothers also expressed the need to be "realistic" about the future; Kraemer and Blacher (2001) examined parents' ideal versus realistic views of the future for their children with intellectual disabilities, finding dissonance between the two, with realistic expectations significantly less ambitious than ideals. The stress and worry described by mothers in this study have also been reported in previous literature (Blacher et al., 2010; Cadman et al., 2012; Orsmond et al., 2006) and contributed to the formation of expectations for their sons' futures.

The third influence theme—stereotypes, stories, and society—demonstrates how the mothers' expectations for their sons' futures have been influenced by external and societal factors. Stereotypes of people with ASD, of teenagers, and of males played a role in how mothers thought about the future, both in how others viewed their sons and how they formed visions of what would be possible in the future. This has theoretical support from the Expectancy-Value Theory of Achievement Motivation (Eccles & Wigfield, 2002) which includes cultural milieu (e.g., stereotypes) and perception of social roles as influential on individuals' expectations for the future. Stories of other people's transitions to adulthood also informed the mothers' expectations for their sons; however, many expressed that there is not enough evidence to feel confident in their beliefs about what their sons' futures could look like. Input from other people—including family members, other mothers, and professionals—also played a role in mothers' expectations for the future; however, they did not always appreciate the

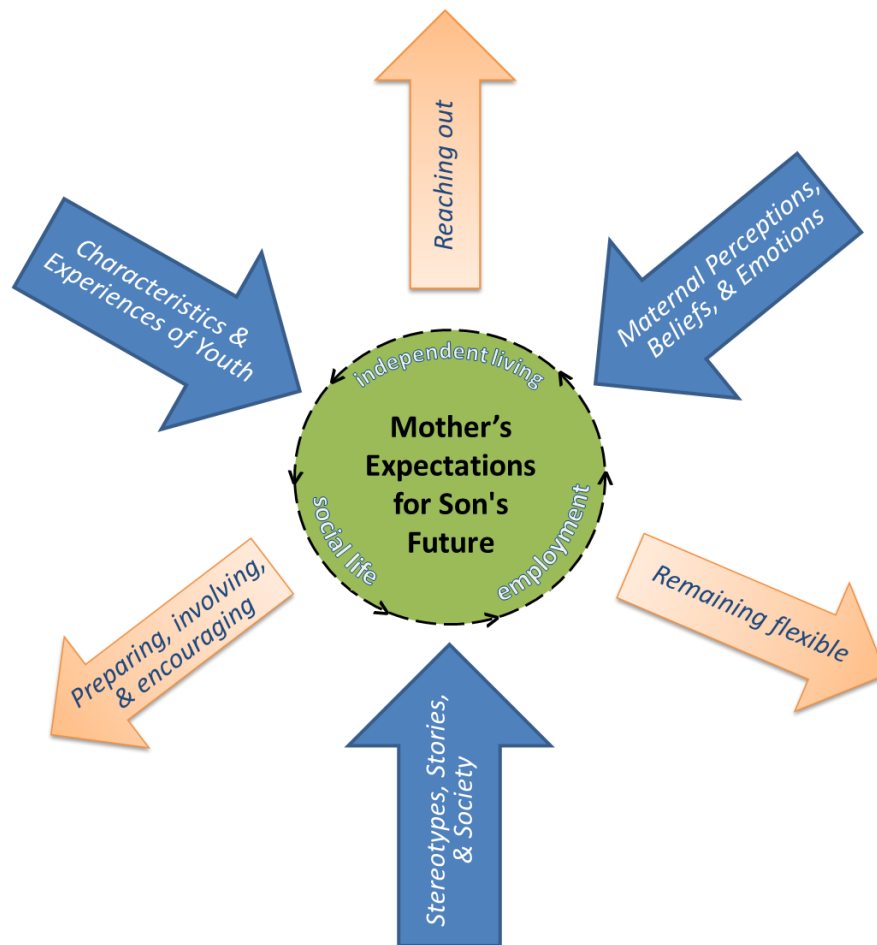
input they were given, and often disagreed, feeling that they know their sons best. Finally, the mothers described negative societal views of ASD and the existence of societal barriers for their sons. Nancy, in particular, discussed her belief in the concept of neurodiversity—a movement which aims to de-emphasize the perception of autism as a disability—and expressed her desires for society to be more accepting, a desire echoed by many of the mothers and others in the literature (Bagatell, 2010; Kapp, Gillespie-Lynch, Sherman, & Hutman, 2013; Robertson, 2010).

Regarding planning for the future, the mothers described three main approaches they use: preparing, involving, and encouraging; remaining flexible and ready to make adjustments; and reaching out to people and resources in the community. These approaches are similar to published recommendations for transition planning, and are interpreted in this study to be reflective of the mothers' expectations as well as the influences on their expectations. The first and third approaches align with guidelines for transition planning published by the National Collaborative on Workforce and Disability (NCWD, n.d.), which advocate, among other things, for: training, preparatory experiences, and support (aligns with Approach 1: preparation, involvement, and encouragement) and role models, mentors, and access to resources (aligns with Approach 3: reaching out). Alternately, Approach 2 (i.e., remaining flexible) is unrelated to standard practices for transition planning, but further reflects the feelings of uncertainty experienced by the mothers in this study about their sons' futures. The necessity of creating back-up plans on a day to day basis—often with great depth and breadth—for families of children with ASD was described by Bagby, Dickie, and Baranek (2012) in a study about sensory experiences and family activities. The need to carefully consider multiple versions of what could happen in the future described in this study is similar but on a much larger scale and is a likely contributor to the stress experienced by families of youth with ASD (Cadman et al.,

2012; Khanna et al., 2012; Orsmond et al., 2006). Additionally, in Approach 3, the need for additional resources was raised by the mothers; they expressed that there were not nearly enough services for their sons in adolescence and expected even less access in adulthood. Previous literature suggests that despite drastic improvements in the amount and quality of services for children with ASD in recent decades, services for adolescents and adults with ASD have not kept pace (Farley et al., 2009; Howlin, Goode, Hutton, & Rutter, 2004; Taylor & Seltzer, 2010) and there is a great need for improved adult services (Eaves & Ho, 2008; Howlin, Moss, Savage, & Rutter, 2013)—in particular, autism-focused services (Taylor & Seltzer, 2011).

Connections across findings. The findings of this study add depth to existing knowledge about the future expectations and transition planning approaches of parents of youth with ASD. Moreover, the inter-connections between the findings identified in this study are notable. It was clear that no influence acted independently in influencing mothers' expectations, that the mothers perceived inherent connections between different aspects of adult life (e.g., social life, living situation, employment, education), and that the approaches being used to address future planning were highly related to mothers' expectations and their influences. Figure 5.1 displays a visual model of the findings of this study which center around mothers' expectations for their sons' futures. As a whole, the model shows the intersections of multiple aspects of this study and how influences, mothers' expectations, and plans for the future act as parts of a larger situation. The influences on mothers' expectations are depicted as arrows directed toward the expectations in the center, which include expectations for their sons' future social lives, employment, and independent living. Arrows representing the approaches face out from the expectations, depicting them as reflective of parent expectations. Circular arrows in the center portray the constant fluidity of all aspects of this process, with all parts holding potential

FIGURE 5.1: Model of Expectations of Mothers of Adolescents with ASD



to influence one another.

It was apparent throughout the interviews that there were inherent connections between the various influences on the mothers' expectations for their sons' futures. For example, the mothers' perceptions, beliefs, and emotions had clearly already had an influence on what opportunities and experiences the youth were given access to in addition to the role they played in influencing their current expectations for the future. Stereotypes, stories, and societal influences had certainly played a role in the thinking and emotions of the mothers, and therefore, on the experiences made available to the youth. Similarly, the youth's characteristics and prior experiences contributed to the mothers' ongoing perceptions, beliefs, and emotions, as well as

the effect external influences (i.e., stereotypes, stories, and society) could have on expectations and planning.

Furthermore, there were clear connections drawn by the mothers between their expectations for different areas of adult life (e.g., social life, employment, living situation). For example, Gabby explained that where George lives in the future will depend on if he drives and how much money he is able to make at a job. Nancy connected hygiene and independence in self-care to social and employment outcomes. Many previous studies have focused specifically on individual outcomes (e.g., employment, participation post-secondary education, residential independence; Chiang et al., 2012; Orsmond et al., 2004; Shattuck et al., 2012), yet these findings lend evidence to support also looking at outcomes across domains (e.g., overall outcomes; Eaves & Ho, 2008; Howlin et al., 2004). Furthermore, future work is warranted to explore how individual outcome domains may influence each other in directional or bidirectional ways.

Finally, the interpretation that approaches to planning are reflective of parent expectations for the future may provide preliminary evidence to explain some of the underlying mechanism behind the relationships between expectations and outcomes identified in previous studies (Carter et al., 2012; Chiang et al., 2012; Doren et al., 2012). Enhanced understanding of what underlies the apparent causal influence of parent expectations on outcomes of adults with ASD can be considered in future research and practice.

Study limitations. This study has a few methodological limitations to consider. First, the sampling method used—convenience sampling through a single organization’s listserv—may have restricted participation to parents who are particularly interested in and concerned about their child’s transition to adulthood. However, there was a considerable amount of diversity in

the experiences, family contexts, and future plans of the families who participated. Furthermore, limiting methods to interviews only, rather than interviews and observations, as well as only conducting one interview per participant could have constrained the depth of understanding reached. Despite these limitations, this study adds new knowledge and richness to extant work examining parent expectations and approaches for the transition planning of youth with ASD.

5.5 Conclusion

The mothers of adolescents with ASD included in this study formed expectations for their sons' adult lives based on factors related to their sons, their own thoughts and beliefs, and influences external to the family. It is notable that their expectations were not merely reflections of the youth's functional skills, as might have been expected. Their expectations about the future social life, employment, and independent living of their sons were all highly interconnected, and their approaches to planning and preparing for the future were interpreted to be reflective of their expectations. The mothers were all actively engaged in preparing their sons to successfully transition to adulthood, all while experiencing pervasive uncertainty about what the future may bring. Consideration of influences, expectations, and approaches within a complex situation adds important context to the existing literature that has examined predictors of outcomes and recommendations for improving transition success.

CHAPTER 6: INTEGRATED DISCUSSION AND CONCLUSIONS

6.1 Introduction

As a whole, this project addressed gaps in the literature related to understanding factors and complex processes influencing the participation outcomes of young adults with autism spectrum disorder (ASD). For the purposes of this project, participation outcomes included the extent of participation in employment, daily living independence, and social relationships, which are commonly reported areas of struggle for adults with ASD. Aspects of the expectancy-value (E-V) model (Eccles & Wigfield, 2002) informed aims related to parent expectations.

Furthermore, a transactional perspective (Cutchin & Dickie, 2012) was used as a broad lens throughout the project to promote full consideration of any aspect that could contribute to one's participation. The incorporation of a transactional perspective also encouraged exploration and consideration of the interconnectedness of factors coordinating together within a broad context. Within and across aims, the current study bolstered understanding of aspects of the lives of individuals with ASD that could lead to supporting improved participation outcomes.

Aim 1 (Chapter 3) laid the groundwork for the project by systematically identifying longitudinal predictors of outcomes within and across three primary domains of participation (i.e., employment, independent living, and social participation) for adults with ASD. Aim 2 (Chapter 4) utilized structural equation modeling to first confirm previously-supported direct relationships from family background and functional performance latent variables to young adult outcomes 10 years later. A parent expectations latent variable was then included in a second

model and was revealed to act as a significant mediator of those relationships. Aim 3 (Chapter 5) expanded upon Aim 2 by qualitatively exploring factors that contribute to the formation of the expectations of parents of adolescents with ASD and provided insight into how expectations may connect with outcomes. The findings across the three aims are integrated in the current chapter and contribute new knowledge about factors influencing participation outcomes of young adults with ASD, interconnections and relationships among factors, and implications for future research and practice.

6.2 Factors Influencing Participation Outcomes

The primary purpose of this overall project was to build a better understanding of factors that influence the participation outcomes of young adults with ASD. The factor most consistently discussed in previous work was IQ, as identified through previous reviews (e.g., Magiati et al., 2014; Seltzer et al., 2004). Across the three studies in this dissertation, however, numerous additional factors were identified which encourage future consideration of characteristics related to the youths with ASD, their families, and their broader situations. These findings also link back to the theoretical perspectives informing the project as well as to the extant literature. For the purposes of integration and discussion, I have categorically grouped key identified factors as: (1) youth's level of functioning; (2) other youth characteristics [gender, age, health]; (3) family characteristics; (4) parent expectations; (5) social influences; and (6) services. Brief summaries of findings related to these factors within and across aims are presented in Table 6.1 and are elaborated on in the following sections.

Youth's level of functioning. The functioning level of youths with ASD was the most commonly identified group of predictors of adult outcomes in the studies reviewed in Chapter 3 and included specific variables such as cognitive level, communication abilities, social skills,

TABLE 6.1: Summary of Key Factors Influencing Outcomes of Young Adults with ASD

	Systematic Review (Aim 1)	NLTS2 Analysis (Aim 2)	Parent Interviews (Aim3)	Integrated Conclusion
<u>Youth's Functioning</u> -IQ/cognition -academics -communication -diagnostic severity -independence level -youth characteristics	Most commonly identified category of factors contributing to outcomes across multiple studies	Direct, significant predictor of outcomes in Model 1 (without parent expectations); however, in Model 2, direct relationship was non-significant, path mediated though parent expectations	Characteristics of the youths (e.g., strengths and challenges) emerged as factors influencing parents' expectations for future outcomes	Although functional performance clearly plays a part in contributing to outcomes, it is not the only group of factors to consider and does not necessarily determine outcomes
<u>Other Characteristics</u> -gender -age -health	Males and older subjects had some poorer outcomes in two NLTS2 studies, and in one, better health was associated with better outcomes	Gender had only indirect relationships with outcomes (via function and expectations), age did not significantly contribute to any variables in the models	Gender stereotypes were mentioned by parents, but not necessarily as indicators of outcomes; depression and anxiety were among concerns	Age and gender associations are generally unclear; physical/mental health status warrant consideration
<u>Family Characteristics</u> -household income -parent education -race/ethnicity -family support -2-parent household -parent characteristics	Identified as significant predictors in some studies using the NLTS2 dataset	Direct, significant predictor of outcomes in Model 1 (without parent expectations); however, in Model 2, direct relationship was non-significant, path mediated though parent expectations	Parents' beliefs, thoughts, and emotions emerged as factors influencing their expectations for future outcomes and thus, the approaches used to prepare	Family characteristics are suggested to contribute to the complex prediction of outcomes, but Aim 3 encourages consideration of more nuanced factors and not merely generalizations
<u>Parent Expectations</u>	Mostly unexplored, but non-significant in multivariate model in one NLTS2 study	Direct, significant predictor of outcomes. Significantly mediates the paths from functional performance and family background to outcomes	Parents' approaches to planning for adulthood are interpreted to help explain the connection between parent expectations and outcomes	Aim 2 provides evidence to suggest parent expectations play a significant mediating role in predicting outcomes, aim 3 provides possible explanation for connections
<u>Social Influences</u>	Teasing by peers was significant in one NLTS2 study	(not included)	Parents perceived social influences as contributors to expected outcomes	Findings suggest factors external to the family should be considered
<u>Services</u>	Some service types significant in two NLTS2 studies	(not included)	Parents discussed positive influences of some services on performance and expectations	Although services likely contribute to outcomes, specifics are lacking

Notes. ASD, autism spectrum disorder. NLTS2, National Longitudinal Transition Study-2.

diagnosis, diagnostic severity, and independence level. At least one variable related to this category was identified as significant in all eight of the included unique studies in predicting employment, social relationships, and/or independent living outcomes for adults with ASD. As one would expect, within the studies there is general consistency in the finding that increased functioning predicts improved outcomes. However, some authors posit that there may be a limit to this relationship; for example, Howlin et al. (2004) identified that having an $IQ \geq 100$ did not necessarily improve participants' outcomes (versus $IQ \geq 70$).

The predictive relationship from functional level to outcomes was partially consistent with the first structural equation model (SEM) described in Chapter 4 (Figure 4.1: Model 1), wherein a latent variable comprised of academic performance, social skills, and self-care skills showed a significant direct path to young adult outcome. However, when a parent expectations variable was entered into an updated model (Figure 4.2: Model 2), the direct relationship between these variables dissipated because it was significantly mediated through parent expectations. This is not to suggest that an individual's functional level does not play a substantial role in their future outcomes, but leaves open the possibility that functional level is not an all-encompassing or purely deterministic predictor and that there may be potential avenues to mitigate deleterious effects and promote more positive outcomes.

During interviews with mothers of youth with ASD (Chapter 5), functional level emerged as a factor related to adult outcomes in an expanded way. Mothers described aspects of their sons with ASD as playing a key role in the development of their expectations for the future and how they envision their sons' adult lives. What the mothers described relates to their functioning level, but added depth and a nuance that is inaccessible with IQ test scores, grades, or other objective measures alone; they described their sons' challenges and past negative experiences as

well as their strengths, interests, preferences, and positive experiences. When scores and grades were mentioned by mothers in the study, their perceived importance was inconsistent.

Specifically, one mother described IQ scores helping her to understand why her son struggled with seemingly simple tasks, another felt frustrated that an IQ test would never reveal what she believed were her son's true gifts, and a third found her son's high IQ to be deceiving because he struggled with everyday functioning despite it.

Overall, although it is clear that functioning level of youth with ASD contributes to their participation outcomes—and makes sense that increased functional level would be associated with improved outcomes—it is important to note that it is not the only factor worth considering and does not definitively determine outcomes. In addition to considering the other factors expanded upon in the following sections, future work should view functional level more broadly than merely with IQ scores; mothers in the qualitative study spoke at length about various aspects of their child's functioning that included—but was not limited to—IQ score. Drawing on findings from the parent interviews and components of E-V theory, it is apparent that there are other important function-related considerations that may influence outcomes such as past work and volunteer experiences, interests and preferences, motivation about the future, daily living skills, social skills, problem solving skills, motivation, and mental health status.

Other youth characteristics. Additional characteristics—specifically, gender, age, and health status—of youths were identified throughout this project as additional potential influences on outcomes, though they were not consistent.

Gender. Gender is a consideration that has been explored in a number of studies, however, study samples usually include small numbers of females because of the unbalanced typical ratio of males to females (currently reported as 4.5:1; CDC, 2014). In fact, three of the

outcome studies included in Chapter 3 did not include any females. As described in Chapter 3, two NLTS2 studies identified poorer participation outcomes among males (less likely to be employed and less socialization with friends); however, this finding is inconsistent (Seltzer et al., 2004) and other studies have suggested females may have poorer outcomes (Taylor & Mailick, 2014). In Chapter 4, direct paths from gender to outcome were tested but not significant in either SEM; however, there was a significant indirect effect of gender on outcomes. Males were identified to have higher functional performance in high school, which led to better outcomes in young adulthood both directly (Model 1) and through their influence on parent expectations (Model 2). Male gender stereotypes were also mentioned by some of the parents during interviews in Chapter 5 as adding confusion for mothers about what to expect in their sons' futures. The field would benefit from future work aimed at better understanding the transition to adulthood process specifically for females with ASD in order to clarify potentially beneficial or unfavorable mutable aspects.

Age. Age is another factor associated with inconsistent findings related to the participation outcomes of adults with ASD. In the systematic review (Chapter 3), one study found increasing age at baseline associated with less social participation (Liptak et al., 2011). Other studies have suggested that employment may increase (Shattuck et al., 2012) or decrease (Taylor & Mailick, 2014) with age in adulthood, and that daily living skills may increase in young adulthood followed by a plateau when individuals are in their late 20s (Smith et al., 2012). In the SEMs in Chapter 4, age did not significantly contribute to any of the variables in either model. It remains possible, however, that age influences outcomes differentially across domains (i.e., improvements in some types of participation and declines in others) or that the age-range included in the NLTS2 (used in Chapter 4 and also in Liptak et al., 2011 and Shattuck et al.,

2012) is not wide enough to capture broad trajectories of change (a greater span of ages included in Taylor & Mailick, 2014 and Smith et al., 2012). During interviews detailed in Chapter 5, many of the participant mothers described perceiving that their sons would take longer to accomplish certain developmental tasks of adulthood. Overall, both age and the amount of time it may take to accomplish adult participation goals remain factors important for consideration.

Health status. The health status of individuals with ASD has also been suggested to influence their adult participation outcomes, though this predictor has not been heavily studied. Two studies included in Chapter 3 explored aspects of health as predictors of outcome; greater overall health and not using prescription medications were found to positively predict employment and social participation with friends in one NLTS2 study (Liptak et al., 2011), but presence of epilepsy at baseline did not predict overall outcome in another study (Billstedt et al., 2005). There was not strong theoretical or empirical rationale for the inclusion of health status in the models tested in Chapter 5, so this variable was not explored. During parent interviews, medication use was described by many mothers to positively influence their sons' functioning and their perceptions of future possibilities. However, mental health concerns (i.e., anxiety and depression) often remained sources of worry for the interviewed mothers; this is not surprising considering the high prevalence of co-morbid psychiatric diagnoses among adolescents and adults with ASD (Ghaziuddin et al., 2002; Levy & Perry, 2011). Thus, findings across studies provide evidence to suggest that both physical and mental health may contribute somewhat to the participation of adults with ASD and should be explored more closely—and with more specificity—in future research. For example, there is a wide variety of prescription medications likely being used and different functions they are prescribed to serve; thus, more detailed

examination would provide additional context to understanding the role that health and the use of medication may play in outcomes.

Family characteristics. Characteristics of the families of youth with ASD are suggested to contribute to their participation outcomes in adulthood. As detailed in Chapter 3, studies using the NLTS2 have identified that the more resources and supports families have available (e.g., higher income, higher parent education, more parent involvement in school, two-parent household), the better their measured outcomes (Chiang et al., 2013; Liptak et al., 2011). Race/ethnicity is also suggested to play a role, with youth who are white (non-Hispanic) experiencing advantaged outcomes (Liptak et al., 2011).

A combined family background latent variable (including white race, household income, and mother's education) was utilized in the models in Chapter 4 and was identified as a significant predictor of functional performance and young adult outcome in Model 1, and functional performance and parent expectations in Model 2. The path from family background to outcome became non-significant with the inclusion of the parent expectations variable, which mediated the relationship. The identification of a significant path from family background to functional performance is consistent with reports of socioeconomic disparities in early services for individuals at risk for ASD (IACC, 2011; Mandell et al., 2007) and can partially explain differences in outcomes. This indirect path does not fully explain variations in outcomes, however; family background had an additional direct relationship to parent expectations which mediated the path to outcomes. Thus, youth from families with more socioeconomic advantages seem to benefit in multiple ways—by receiving earlier (and likely higher-quality) ASD-related services contributing to improved functional performance as well as from more positive parent expectations. Parent expectations for outcomes may differ as a function of family background

variables due to cultural influences as well as parents' personal experiences (e.g., a mother who has struggled to financially support herself likely doubts her child with a disability will be able to successfully do so).

During the qualitative interviews, it became clear that the mothers' perceptions, beliefs, and emotions influenced their expectations for their sons' futures. These aspects of the mothers' experiences may be somewhat related to the family background variables explored in other studies. Anecdotally, however, it seems that these broadly-defined, categorical variables (i.e., race, income) may be overgeneralizations that do not do well to characterize individuals. For example, the two mothers in Chapter 5 who reported being in the highest income bracket—both with two-parent, highly-educated households and sharing the same racial identity (white)—seemed to have completely opposite expectations and values for the future; one placed utmost importance on safety and described feeling grateful they had the finances to support their son as an adult while the second emphasized the necessity of their son financially supporting himself and leaving the family home.

In sum, family characteristics have been shown to contribute to outcomes of adults with ASD, but there is evidence that their influence is related to earlier functional limitations (possibly conflated with limited access to quality services) as well as parents' perceptions about what is possible for their children. From a practical standpoint, individualization seems crucial to effectively address the unique needs of families; however, from a broad perspective, improved access to early (as well as later) service provision is needed help improve youths' functioning and contribute to improved participation outcomes in adulthood.

Parent expectations. Parents' expectations for the adult participation outcomes of their adolescent children with ASD were of particular interest in the current project. Empirical

research has suggested that parent expectations can predict to individual participation outcomes (e.g., participation in employment) for youth with disabilities (Carter et al., 2012; Doren et al., 2012), but the complex nature of the construct of parent expectations remains somewhat elusive. In Chapter 4, I explored—and confirmed—parent expectations as a mediator of the paths from family background and functional performance to young adult outcome. This analysis also directly answered sub-questions about what factors predict parent expectations and if parent expectations predict outcomes. Parental expectations which included their expectations of paid employment and residential independence in the future were, indeed, found to significantly and directly predict the combined young adult outcome variable. Furthermore, family background and functional behavior variables were identified to significantly predict expectations. Chapter 5 added further to this topic by elaborating upon factors that may contribute to the development of parent expectations as well as by elucidating how expectations may influence outcomes. Through discussion with mothers in the study, it became apparent that their expectations for the future influenced the approaches they were taking to prepare for their sons' futures, and that this was likely part of the mechanism through which expectations influence outcomes.

The findings of this study expand upon what was previously known about the role of parent expectations in predicting outcomes of youth with ASD. However, the essence of this construct is not fully understood. Specifically, it is unclear whether expectations are something unique on their own that could be the target of intervention for improved outcomes or if parent expectations are essentially just a manifestation of other variables. If the latter, variables that could be considered and targeted include family background variables (via improved policy and access for underserved individuals), functional performance (via targeted educational and/or therapeutic interventions), and social barriers (via education and training for people in the

community including potential employers). Furthermore, approaches—which are believed to connect expectations with outcomes—could be directly targeted. What seems to hold the most potential for leading to meaningful improvements in outcome, however, is addressing expectations in conjunction with one or more of these other constructs.

Social influences. Social influences were not closely examined in the current study, but there is some evidence to suggest that broader social/societal factors contribute to the participation outcomes of adults with ASD. One NLTS2 publication included in Chapter 3 reported a significant relationship between having been teased by peers and employment outcome. Additionally, mothers in Chapter 5 described social and societal influences on the development of their expectations for their sons' futures. These factors seemed to contribute to the mothers' expectations for adult outcomes in diverse ways, with some external factors perceived as barriers or challenges for their sons (e.g., lack of understanding and acceptance of people with ASD), others encouraging hope (e.g., stories of adults with ASD viewed as successful), and still more leading to confusion and uncertainty about the future (e.g., sons not conforming to stereotypes of people with ASD).

There is also theoretical support for the role of social influences on performance, development, and participation. The transactional perspective (Cutchin & Dickie 2012), used as a lens in the current project, certainly supports the consideration of all aspects of the environment as moving parts of the broader situation in constant coordination with adolescents and adults with ASD and their families. More specifically, expectancy-value theory posits that cultural milieu including stereotypes and the beliefs and behaviors of others can influence expectations as well as choices about performance (Eccles & Wigfield, 2002). There are also additional theories and conceptual models relevant to this topic that were not used to guide or frame the current

project, but nonetheless lend support to the relevance of this category of influence. For example, Broffebrenner's (1979) Ecological Systems Theory is a widely recognized model of child development that explicates how increasingly broad environmental systems influence a child's growth and development. Finally, the conceptual model of the International Classification of Functioning, Disability and Health (ICF; WHO, 2001) suggests that one's social and attitudinal environment holds potential to influence their participation.

Services. A final influence category that emerged during the project was services, though the contribution of services to outcomes was only shallowly explored. Publications from the NLTS2 explored the role of school services on outcomes, specifically identifying that career counseling in high school positively predicted employment (Chiang et al., 2013). Howlin et al. (2013) found a non-significant relationship between attending a specialized autism school and overall outcome. Services were not explored in Chapter 4, although, it is likely—as mentioned previously—that access to services at an earlier age contributed to the relationship between family background variables and functional performance at baseline. Services and service providers were discussed by mothers of youth with ASD during qualitative interviews in Chapter 5; many of the mothers reported positive influences of certain services (e.g., psychological counseling, job training services) on their expectations. However, they also conveyed frustration with some existing services and a general desperation for increased and improved services for adolescents and adults with ASD. Although it is probable that high quality, relevant services contribute to improved outcomes, there is a dearth of specific information about the types and necessary components of beneficial services.

6.3 Interconnectedness and Relationships among Factors

An important finding of this project is around the complexity inherent in the transition process and in predicting the participation outcomes of young adults with ASD. Specifically, it was apparent across studies that many aspects of the process held potential to influence many other aspects. This is congruent with the transactional perspective (Cutchin & Dickie, 2012) which contributed to informing this project at the outset. Using this lens meant taking a perspective that individuals and their surroundings are constantly in flux and transacting as part of a broader situation. This viewpoint led to closer consideration of relationships among outcome variables, attention to the potential for bidirectional effects of influential factors, and working toward a comprehensive model of the relationships explored in this project.

Relationships among outcome variables. Researchers have addressed the measurement of participation outcomes of adults with ASD in two main ways—utilizing individual variables or domains and/or looking across domains at an overall rating. The findings of the current study support the use of overall outcomes encapsulating participation in employment, daily living independence, and social relationships for the purposes of identifying factors that predict outcomes. In Chapter 3, predictor variables were found to be generally consistent across domains. Furthermore, Chapter 4 demonstrated successful creation of an outcomes latent variable including indicators of these domains, with each indicator loading significantly. These findings indicate that there is substantial similarity in the patterns of outcomes across domains which could be interpreted as evidence for shared mechanisms for these outcomes.

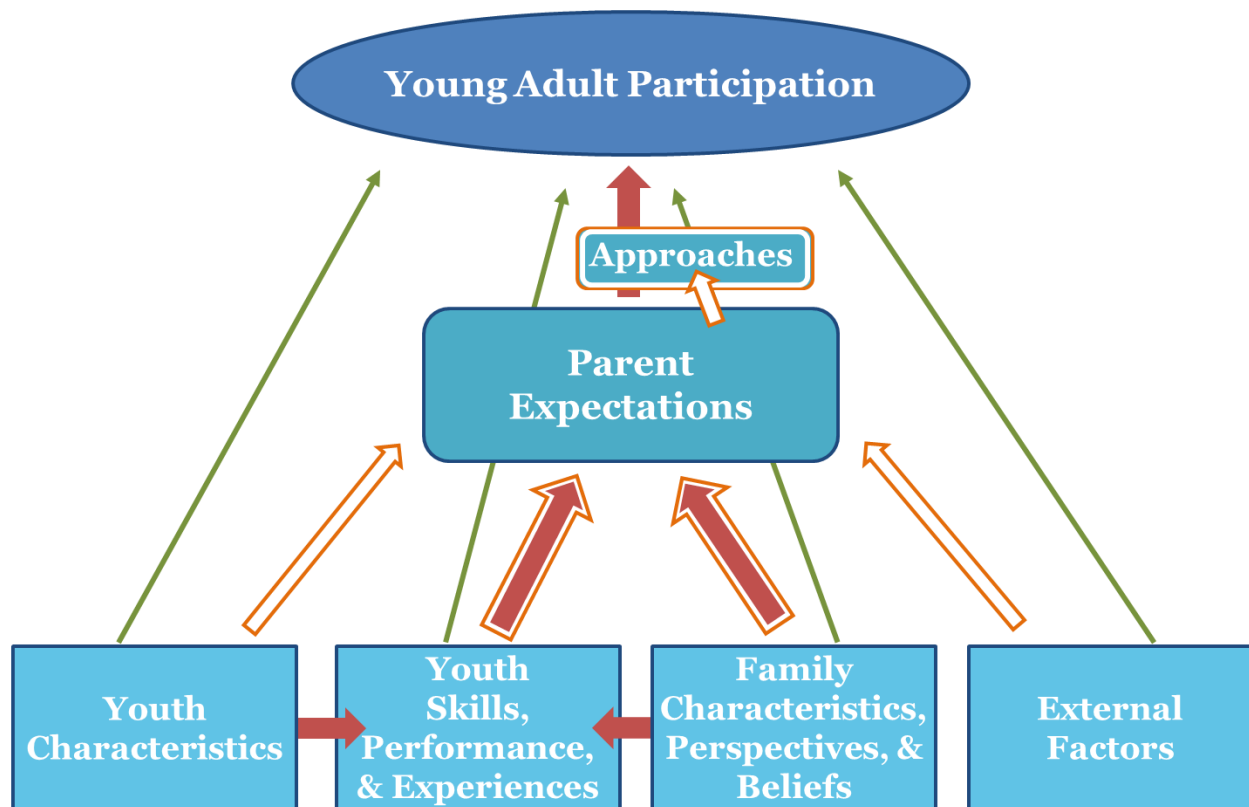
However, it is also possible that in addition to sharing some mechanisms, these variables influence each other in uni- or bi-directional patterns. During the qualitative interviews reported in Chapter 5, mothers' visions for their sons' outcomes were often described as contingent upon

one another. For example, some mothers explained that their sons' living arrangements would depend on whether or not they could support themselves financially and that social relationships could depend on where they worked and lived. Ultimately, it may be difficult to parse out which outcome variables may predict to which others; however, the question holds relevance both theoretically and clinically and warrants continued consideration.

Bidirectional effects within the processes leading to outcomes. Although the reviewed studies in Chapter 3 and the models run in Chapter 4 focused on uni-directional relationships between factors influencing outcomes for adults with ASD, findings from the interviews described in Chapter 5 were not so straightforward. The themes identified as contributors to the development of parent expectations (i.e., characteristics and experiences of youth; maternal perceptions, beliefs, and emotions; and stereotypes, stories, and society) each seemed to hold potential to interact with each other and contribute to parent expectations in a bidirectional manner. For example, it was apparent that mothers' values, beliefs, and expectations had influenced what experiences each youth had been exposed to, and conversely, the youths' characteristics and past experiences played a role in shaping the beliefs and emotions of mothers. External factors such as social influences likely contributed to the development of maternal perceptions, beliefs, and emotions as well as youths' opportunities and experiences. Alternately, youth and maternal characteristics may have influenced the extent to which external factors contributed to their experiences. These considerations are all highly transactional and contribute to the important understanding that these complex processes may not be able to be neatly explained in a comprehensive manner.

Toward a comprehensive model. Figure 6.1 contains a simplified visual representation of the identified relationships between constructs across the aims of the current project, with the

FIGURE 6.1: Model of Influences on Participation Outcomes of Young Adults with ASD



primary intention to explain relationships among factors influencing the participation outcomes of youth with ASD. Factors are grouped conceptually as in Table 6.1 except that social influences and services are merged (i.e., external factors) in the figure. Relationships between factor groupings as identified in each study are merged to contribute to an overall understanding of the dissertation findings. Note that not all details about potential connections that were previously described are shown (e.g., relationships between each of the qualitative themes and between domains of participation outcomes). The bottom row of factors and thin green arrows represent outcome predictors and relationships identified through the systematic review of the literature in Chapter 3. Next, the thick red arrows represent relationships identified through the structural equation modeling analysis using NLTS2 data in Chapter 4. As displayed, although

there are four thin green arrows leading to young adult participation, none of these relationships are reproduced with the thicker red arrows (i.e., in the NLTS2 analysis) because the influence of those variables (i.e., gender, functional skills, and family background) was mediated through others, and only parent expectations revealed a significant, direct relationship to outcomes. Lastly, the orange-outlined arrows represent the relationships that emerged from the qualitative interviews with mothers of youth with ASD, adding nuance to understanding influences on parent expectations. Additionally, approaches were introduced by the mothers during their interviews and reflected their expectations; this finding contributes to explaining the process by which expectations predict outcomes. When viewing this model, it is apparent that parent expectations are an important, yet complex, piece of the puzzle to consider regarding predictability of outcomes for young adults with ASD.

6.4 Implications for Future Research and Practice

The scholarly discipline of occupational science concerns performance of and participation in occupations, or the activities of life. This project contributes new knowledge to occupational science, focused on factors that influence or predict participation in occupations—specifically, occupations related to work, social engagement, and everyday living. In particular, this project identified factors related to occupational participation including individuals’ performance-related features, demographic characteristics, and various external influences. Furthermore, this project focused in depth on parents’ expectations for their children’s futures as a factor that influences participation in occupations for youth with ASD. Previous work in occupational science has explored concepts that influence participation in occupations, such as Rudman’s work on occupational possibilities which explicates how remote societal forces impact what occupations are possible for people to engage in (Rudman, 2010). This work extends that

idea by adding expectations of participation as a consideration in understanding the nature of occupational engagement. In Chapter 4, parent expectations were identified as a significant mediator of later participation and Chapter 5 provided evidence to help explain this relationship, with expectations influencing approaches to planning for the future. Future work in occupational science should further explore how individuals' own expectations or the expectations of those in their lives—particularly caregivers—contribute to occupational development, performance, and participation in various populations.

The findings of the current project as a whole also point to a number of implications for future interdisciplinary research related to adolescents and adults with ASD. First, there remains an inconclusive relationship between gender and participation outcomes for adults with ASD. The confusion may be due to the small female sample sizes typical in outcome studies. Thus, there is a need for future research to focus more overtly on how females with ASD experience the transition planning process and if they have unique needs during the transition and in adulthood. Second, although health status was explored in some NLTS2 studies, there is a need to more specifically examine the contributions of mental health factors (i.e., depression and anxiety) as well as medication self-management to the transition process and outcomes for adults with ASD. Mothers in the qualitative study spoke positively about their sons' medications, but maintained serious concerns that they would fail to take their medications consistently which would result in major problems. Third, a general need was identified for more research on effective services that can improve meaningful adult participation outcomes.

I placed a great deal of emphasis in the current study on examining parent expectations as a potential contributor to young adult outcome; this potential contributor was emphasized in part because I perceived expectations as a potentially malleable construct (e.g., through parent

education or counseling). Parent expectations were explored in Chapters 4 and 5, adding new knowledge about what contributes to their formation as well as the role they play in shaping approaches to preparing for adulthood and in predicting young adult outcomes. These expectations are not necessarily static; in fact, some mothers in the qualitative study did suggest that their expectations had changed or been adjusted over time. However, the extent to which expectations could be meaningfully altered through intervention is unknown. As previously explained (Section 6.2), I posit that development of interventions to target parent expectations in conjunction with youths' functional skills may have unique potential to produce meaningful improvements in outcome. This holds potential for both future research and practice.

The most salient implication from this project for practitioners is the notion that outcomes are not rigidly determined by the functional skills and performance of the youth with ASD. Thus, it is critical that professionals working with individuals with ASD during the transition to adulthood—and especially those working to provide transition-related support—consider the multitude of factors explored in the current study. Professionals should also be conscious of the fact that they themselves act as a part of youths' broader situations and that their services as well as their social influence could contribute to participation outcomes. Families should be educated about factors that may promote more successful outcomes and those that may be detrimental to outcomes in order to work toward mitigating those effects. In particular, parents should be informed about the potential influence of their expectations on outcomes and practitioners should make a concerted effort to understand parents' expectations as well as factors that have contributed to their formation. Parents and practitioners should work together to determine if expectations may need readjustment or if they seem realistic considering the broader situation.

This project as a whole represents significant progress toward development of a deeper understanding of factors and processes that contribute to the participation outcomes of young adults with ASD. Aspects of this knowledge can be directly applied to practice; however, future research is also warranted to expand upon this body of knowledge and to contribute to the development of improved policies and services to support the meaningful participation of adolescents and adults with ASD.

APPENDIX A: SEMI-STRUCTURED INTERVIEW GUIDE

- I would like to hear about how you envision your son's future. What do you think life will be like for him? What kinds of things do you think he will be doing after leaving high school? [probed as needed for discussion of work, school, living, social]
- Are there aspects of his future that you are uncertain about?
- Are there aspects of his future that you are especially concerned about?
- What kinds of things do you think have influenced what you think he can and will do in the future?
- Are there any things that you think could happen that would change how you see his future?
- Have your expectations for his future changed since he was a child? Or more recently?

APPENDIX B: CAREGIVER QUESTIONNAIRE

The following questions are about the youth included in the study:

Youth's age: _____ years

Youth's sex: ☐ Male ☐ Female

Is youth from a Hispanic/Latino background? ☐ Yes ☐ No

Youth's race (check all that apply):

☐ Caucasian

☐ Asian

☐ African American/Black

☐ Other (fill-in) _____

Youth's expected date of leaving high school: _____ (month) _____ (year)

The following questions are about you:

Your relationship to youth (example: biological mother): _____

Your age: _____ years

Your sex: ☐ Male ☐ Female

Are you from a Hispanic/Latino background? ☐ Yes ☐ No

Your race (check all that apply):

☐ Caucasian

☐ Asian

☐ African American/Black

☐ Other (fill-in) _____

What range represents the yearly income for your household?

☐ less than \$29,000

☐ \$30,000 – \$79,000

☐ more than \$80,000

Future Questions:

How likely do you think it is that this youth will do each of the following activities in the future?
(Circle the number that matches your response)

	Definitely won't	Probably won't	Probably will	Definitely will	Already has done	Don't know
Get a driver's license	1	2	3	4	5	-
Graduate from high school with a regular diploma	1	2	3	4	5	-
Attend school after high school	1	2	3	4	5	-
Complete a technical or trade school program	1	2	3	4	5	-
Graduate from a 2-year or junior college	1	2	3	4	5	-
Graduate from a 4-year college or university	1	2	3	4	5	-
Live away from home on his/her own without supervision	1	2	3	4	5	-
Live away from home on his/her own <u>with</u> supervision	1	2	3	4	5	-
Have a romantic partner*	1	2	3	4	5	-
Participate in social activities outside of school, work, and family functions*	1	2	3	4	5	-
Get a paid job	1	2	3	4	5	-
Get a paid job and earn enough to support him/herself without financial help from his/her family or the government	1	2	3	4	5	-

Notes. These questions are based on the NLTS2 wave 1 parent survey. *, new questions added for the purposes of this study

REFERENCES

- Altman, D. G. (2001). Systematic reviews of evaluations of prognostic variables. *British Medical Journal*, 323, 224-228.
- American Psychological Association (APA) (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: Author.
- Anderson, D. K., Liang, J. W., & Lord, C. (2014). Predicting young adult outcome among more and less cognitively able individuals with autism spectrum disorders. *The Journal of Child Psychology and Psychiatry*, 55(5), 485-494.
- Ankeny, E. M., Wilkins, J., & Spain, J. (2009). Mothers' experiences of transition planning for their children with disabilities. *Council for Exceptional Children*, 41(6), 28-36.
- Arnett, J. J. (2000). Emerging adulthood: A theory of development from the late teens through the twenties. *American Psychologist*, 55(5), 469-480.
- Arnett, J. J. (1997). Young people's conceptions of the transition to adulthood. *Youth Society*, 29, 3-23.
- Arnett, J. J. (1994). Are college students adults? Their conceptions of the transition to adulthood. *Journal of Adult Development*, 1(4), 213-224.
- Bagatell, N. (2007). Orchestrating voices: Autism, identity and the power of discourse. *Disability & Society*, 22(4), 413-426.
- Bagatell, N. (2010). From cure to community: Transforming notions of autism. *Ethos*, 38(1), 33-55.
- Bagatell, N. J., Cram, M., Alvarez, C. G., & Loehle, L. (2014). Routines of families with adolescents with autistic disorders: A comparison study. *Canadian Journal of Occupational Therapy*, 81(1), 62-67.
- Bagby, M. S., Dickie, V. A., & Baranek, G. T. (2012). How sensory experiences of children with and without autism affect family occupations. *American Journal of Occupational Therapy*, 66, 78-86.
- Baker, J. P. (2013). Autism at 70—Redrawing the boundaries. *The New England Journal of Medicine*, 369, 1089-1091.
- Banerjee, A., Chitnis, U. B., Jadhav, S. L., Bhawalkar, J. S., & Chaudhury, S. (2009). Hypothesis testing, type I and type II errors. *Industrial Psychiatry Journal*, 18, 127-131.
- Baron-Cohen, S., Scott, F. J., Allison, C., Williams, J., Bolton, P., Matthews, F. E., & Brayne, C. (2009). Prevalence of autism-spectrum conditions: UK school-based population study. *British Journal of Psychiatry*, 194, 500-509.

- Bauman, M. L. (2010). Medical comorbidities in autism: Challenges to diagnosis and treatment. *Neurotherapeutics: The Journal of the American Society for Experimental NeuroTherapeutics*, 7, 320-327.
- Betancur, C. (2011). Etiological heterogeneity in autism spectrum disorders: More than 100 genetic and genomic disorders and still counting. *Brain Research*, 1380, 42-77.
- Betz, N. E., & Hackett, G. (1983). The relationship of mathematics self-efficacy expectations to the selection of science-based college majors. *Journal of Vocational Behavior*, 23, 329-345.
- Biesta, G. (2010). Pragmatism and the philosophical foundations of mixed methods research. In A. Tashakkori & C. Teddlie (Eds.), *The Sage handbook of mixed methods in social & behavioral research* (pp. 95-118). Thousand Oaks, CA: Sage.
- Billstedt, E., Gillberg, I. C., & Gillberg, C. (2011). Aspects of quality of life in adults diagnosed with autism in childhood: A population-based study. *Autism*, 15(1), 7-20.
- Billstedt, E., Gillberg, C., & Gillberg, C. (2005). Autism after adolescence: Population-based 13- to 22-year follow-up study of 120 individuals with autism diagnosed in childhood. *Journal of Autism and Developmental Disorders*, 35, 351-360.
- Bishop, D. V. M. (2010). Overlaps between autism and language impairment: Phenomimicry or shared etiology? *Behavioral Genetics*, 40, 618-629.
- Blacher, J., Kraemer, B. R., & Howell, E. J. (2010). Family expectations and transition experiences for young adults with severe disabilities: Does syndrome matter? *Advances in Mental Health and Learning Disabilities*, 4(1), 3-16.
- Blumberg, S. J., Bramlett, M. D., Kogan, M. D., Schieve, L. A., Jones, J. R., & Lu, M. C. (2013). Changes in prevalence of parent-reported autism spectrum disorder in school-aged U. S. children: 2007 to 2011-2012. *National Health Statistics Reports*, 65, 1-11.
- Boisvert, R. D. (1998). *John Dewey: Rethinking our time*. Albany, NY: SUNY Press.
- Bolte, S. (2014). The power of words: Is qualitative research as important as quantitative research in the study of autism? *Autism*, 18(2), 67-68.
- Bowen, N. K., & Guo, S. (2012). *Structural equation modeling*. New York, NY: Oxford University Press.
- Brantlinger, E., Jimenez, R., Klingner, J., Pugach, M., & Richardson, V. (2005). Qualitative studies in special education. *Council for Exceptional Children*, 71(2), 195-207.
- Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design*. Cambridge, MA: Harvard University Press.

- Bruininks, R. H., Woodcock, R. W., Weatherman, R. F. & Hill, B. K. (1984). *Scales of independent behavior-Revised*. Rolling Meadows, IL: Riverside Publishing Company.
- Cadman, T., Eklund, H., Howley, D., Hayward, H., Clarke, H., Findon, J...Glaser, K. (2012). Caregiver burden as people with autism spectrum disorder and attention-deficit/hyperactivity disorder transition into adolescence and adulthood in the United Kingdom. *Journal of the American Academy of Child and Adolescent Psychiatry*, 51, 879-888.
- Carter, E. W., Austin, D., & Trainor, A. A. (2012). Predictors of postschool employment outcomes for young adults with severe disabilities. *Journal of Disability Policy Studies*, 23, 50-63.
- Cederlund, M., Hagberg, B., Billstedt, E., Gillberg, I.C., & Gillberg, C. (2008). Asperger syndrome and autism: A comparative longitudinal follow-up study more than 5 years after original diagnosis. *Journal of Autism and Developmental Disorders*, 38, 72-85.
- Centers for Disease Control and Prevention (CDC) (2014). Prevalence of autism spectrum disorder among children aged 8 years—Autism and developmental disabilities monitoring network, 11 sites, United States, 2010. *Morbidity and Mortality Weekly Report*, 63(2), 1-21.
- Centers for Disease Control and Prevention (CDC) (2012). Prevalence of autism spectrum disorders—Autism and developmental disabilities monitoring network, 14 sites, United States, 2008. *Morbidity and Mortality Weekly Report*, 61(3), 1-19.
- Chiang, H.-M., Cheung, Y. K., Hickson, L., Xiang, R., & Tsai, L. Y. (2012). Predictive factors of participation in postsecondary education for high school leavers with autism. *Journal of Autism and Developmental Disorders*, 42, 685-696.
- Chiang, H.-M., Cheung, Y. K., Li, H., & Tsai, L. Y. (2013). Factors associated with participation in employment for high school leavers with autism. *Journal of Autism and Developmental Disorders*, 43, 1832-1842.
- Cimera, R. E., & Cowan, R. J. (2009). The costs of services and employment outcomes achieved by adults with autism in the US. *Autism*, 13, 285-302.
- Clark, F. A., Parham, D., Carlson, M. E., Frank, G., Jackson, J., Pierce, D., ...Zemke, R. (1991). Occupational science: Academic innovation in the service of occupational therapy's future. *American Journal of Occupational Therapy*, 45, 300-310.
- Coffey, A., & Atkinson, P. (1996). *Making sense of qualitative data: Complementary research strategies*. Thousand Oaks, CA: Sage Publications, Inc.
- Constantino, J. N., & Gruber, C. P. (2005). *The social responsiveness scale manual*. Los Angeles, CA: Western Psychological Services.

- Cornelius, L. R., van der Klink, J. J., Groothoff, J. W., & Brouwer, S. (2011). Prognostic factors of long term disability due to mental disorders: A systematic review. *Journal of Occupational Rehabilitation*, 21, 259–274.
- Cutchin, M. P., & Dickie, V. A. (2012). Transactionalism: Occupational science and the pragmatic attitude. In G. Whiteford & C. Hocking (Eds.), *Critical perspectives on occupational science: Society, inclusion, participation* (pp. 23-37). London: Wiley.
- Daley, T. C. (2004). From symptom recognition to diagnosis: Children with autism in urban India. *Social Science & Medicine*, 58, 1323-1335.
- Daly, K. (2007). *Qualitative methods for family studies and human development*. Thousand Oaks, CA: Sage Publications, Inc.
- Daniels, J. (2006). Autism and the environment. *Environmental Health Perspectives*, 114, A396.
- Dawson, G., Hill, D., Spencer, A., Galpert, L., & Watson, L. (1990). Affective exchanges between young autistic children and their mothers. *Journal of Abnormal Child Psychology*, 18(3), 335-345.
- DeGrace, B. W. (2004). Families, children with autism and everyday occupations. *American Journal of Occupational Therapy*, 58, 543-550.
- DiCicco-Bloom, E., Lord, C., Zwaigenbaum, L., Courchesne, E., Dager, S. R., Schmitz, C., ... Young, L. J. (2006). The developmental neurobiology of autism spectrum disorder. *The Journal of Neuroscience*, 26, 6897-6906.
- Dickie, V., Cutchin, M. P., & Humphry, R. (2006). Occupational as transactional experience: A critique of individualism in occupational science. *Journal of Occupational Science*, 13, 83-93.
- Doren, B., Gau, J. M., & Lindstrom, L. E. (2012). The relationship between parent expectations and postschool outcomes of adolescents with disabilities. *Exceptional Children*, 79(1), 7-23.
- Dunn, L. M., Dunn, L. M., Bulheller, S., & Häcker, H. (1965). *Peabody picture vocabulary test*. Circle Pines, MN: American Guidance Service.
- Eaves, L. C., & Ho, H. H. (1997). School placement and academic achievement in children with autistic spectrum disorders. *Journal of Developmental and Physical Disabilities*, 9(4), 277-291.
- Eaves, L. C. & Ho, H. H. (2008). Young adult outcome of autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 38, 739-749.
- Eccles (Parsons), J., Adler, T. F., Futterman, R., Goff, S. B., Kaczala, C. M., Meece, J. L., & Midgley, C. (1983). Expectancies, values, and academic behaviors. In T. Spence (Ed.),

- Achievement and achievement motivation* (pp. 75-146). San Francisco, CA: W. H. Freeman.
- Eccles, J. S., Barber, B., & Jozefowicz, D. (1999). Linking gender to educational, occupational, and recreational choices: Applying the Eccles et al. model of achievement-related choices. In W. B. Swann, J. H. Langlois, & L. A. Gilbert (Eds.), *Sexism and stereotypes in modern society* (pp. 153-192). Washington, DC: American Psychological Association.
- Eccles, J. S., & Wigfield, A. (2002). Motivational beliefs, values, and goals. *Annual Review of Psychology*, 53, 109-132.
- Elder, G. H. (1994). Time, human agency, and social change: Perspectives on the life course. *Social Psychology Quarterly*, 57(1), 4-15.
- Esbensen, A. J., Bishop, S. L., Seltzer, M. M., Greenberg, J. S., & Taylor, J. L. (2010). Comparisons between individuals with autism spectrum disorders and individuals with Down syndrome in adulthood. *American Journal on Intellectual and Developmental Disabilities*, 115(4), 277-290.
- Farley, M. A., McMahon, W. M., Fombonne, E., Jenson, W. R., Miller, J. Gardner, M., ... Coon, H. (2009). Twenty-year outcome for individuals with autism and average or near-average cognitive abilities. *Autism Research*, 2, 109-118.
- Fawcett, J., & Downs, F. (1986). *The relationship of theory and research*. Norwalk, CT: Appleton Century Crofts.
- Fein, D., Barton, M., Eigsti, I. M., Kelley, E., Naigles, L., Schultz, R. T., ... Tyson, K. (2013). Optimal outcome in individuals with a history of autism. *Journal of Child Psychiatry and Psychology*, 54(2), 195-205.
- Fountain, C., King, M. D., & Bearman, P. S. (2011). Age of diagnosis for autism: Individual and community factors across 10 birth cohorts. *Journal of Epidemiology and Community Health*, 65, 503-510.
- Frame, J. D. (2013). *Framing decisions: Decision-making that accounts for irrationality, people, and constraints*. San Francisco, CA: Jossey Bass.
- Friese, S. (2011). *ATLAS.ti 6 user manual*. Berlin, Germany: ATLAS.ti Scientific Software Development GmbH.
- Georgiades, S., Szatmari, P., & Boyle, M. (2013). Editorial: Importance of studying heterogeneity in autism. *Neuropsychiatry*, 3(2), 123-125.
- Gergen, K. J. & Gergen, M. M. (2008). Social construction and psychological inquiry. In J. A. Holstein & J. F. Gubrium (Eds.), *Handbook of constructionist research* (pp. 13-39). New York, NY: The Guilford Press.

- Ghaziuddin, M., Ghaziuddin, N., & Greden, J. (2002). Depression in persons with autism: Implications for research and clinical care. *Journal of Autism and Developmental Disorders*, 32(4), 299-306.
- Gillespie-Lynch, K., Sepeta, L., Wang, Y., Marshall, S., Gomez, L., Sigman, M., & Hutman, T. (2012). Early childhood predictors of the social competence of adults with autism. *Journal of Autism and Developmental Disorders*, 42, 161-174.
- Grigal, M., & Neubert, D. A. (2004). Parents' in-school values and post-school expectations for transition-aged youth with disabilities. *Career Development for Exceptional Individuals*, 27, 65-85.
- Haertl, K., Callahan, D., Markovics, J., & Sheppard, S. S. (2013). Perspectives of adults living with autism spectrum disorder: Psychosocial and occupational implications. *Occupational Therapy in Mental Health*, 29(1), 27-41.
- Hagberg, B. S., Nydén, A., Cederlund, M., & Gillberg, C. (2013). Asperger syndrome and “non-verbal learning problems” in a longitudinal perspective: Neuropsychological and social adaptive outcome in early adult life. *Psychiatry Research*, 210, 553-558.
- Harrington, J. W., Patrick, P. A., Edwards, K. S., & Brand, D. A. (2006). Parental beliefs about autism: Implications for the treating physician. *Autism*, 10, 452-462.
- Hendricks, D. R. & Wehman, P. (2009). Transition from school to adulthood for youth with autism spectrum disorders: Review and recommendations. *Focus on Autism and Other Developmental Disabilities*, 24(2), 77-88.
- Henninger, N. A., & Taylor, J. L. (2013). Outcomes in adults with autism spectrum disorders: A historical perspective. *Autism*, 17, 103-116.
- Hogan, D. P., & Astone, N. M. (1986). The transition to adulthood. *Annual Review of Sociology*, 12, 109-130.
- Hollinger, C. L. (1983). Self-perception and the career aspirations of mathematically talented female adolescents. *Journal of Vocational Behavior*, 22, 49-62.
- Holwerda, A., van der Klink, J. J. L., Groothoff, J. W., & Brouwer, S. (2012). Predictors for work participation in individuals with an autism spectrum disorder: A systematic review. *Journal of Occupational Rehabilitation*, 22, 333-352.
- Howlin, P., Goode, S., Hutton, J., & Rutter, M. (2004). Adult outcome for children with autism. *Journal of Child Psychology and Psychiatry*, 45, 212-229.
- Howlin, P., Mawhood, L., & Rutter, M. (2000). Autism and developmental receptive language disorder—A follow-up comparison in early adult life. II: Social, behavioural, and psychiatric outcomes. *Journal of Child Psychology & Psychiatry*, 41, 561-578.

- Howlin, P., & Moss, P. (2012). Adults with autism spectrum disorders. *Canadian Journal of Psychiatry*, 57, 275-283.
- Howlin, P., Moss, P., Savage, S., & Rutter, M. (2013). Social outcomes in mid- to later adulthood among individuals diagnosed with autism and average nonverbal IQ as children. *Journal of the American Academy of Child & Adolescent Psychiatry*, 52, 572-581.
- Humphry, R. (2005). Model of processes transforming occupations: Exploring societal and social influences. *Journal of Occupational Science*, 12(1), 36-44.
- IBM (2013). IBM SPSS Statistics for Windows, Version 22.0. Armonk, NY: IBM Corp.
- Individuals with Disabilities Education Improvement Act (IDEA) (2004), H.R. 1350, 108th Congress.
- Institute of Education Sciences (IES) (n.d.). *Welcome to NLTS2*. Retrieved from www.nlts2.org
- Institute of Medicine of the National Academies (IOM) (2011). *Finding what works in health care: Standards for systematic reviews*. Retrieved from www.iom.edu/srstandards
- Interagency Autism Coordinating Committee (IACC) (2013). *IACC strategic plan for autism spectrum disorder research: 2013 update*. Retrieved from <http://iacc.hhs.gov/strategic-plan/2013/index.shtml>
- Interagency Autism Coordinating Committee (IACC) (2012). *IACC/OARC autism spectrum disorder publications analysis: The global landscape of autism research*. Retrieved from <http://iacc.hhs.gov/publications-analysis/july2012/index.shtml>
- Interagency Autism Coordinating Committee (IACC) (2011). *IACC strategic plan for autism spectrum disorder research*. Retrieved from <http://iacc.hhs.gov/strategic-plan/2011/index.shtml>
- Joas, H. (1993). *Pragmatism and social theory*. Chicago, IL: University of Chicago Press.
- Johnson, B. & Gray, R. (2010). A history of philosophical and theoretical issues for mixed methods research. In A. Tashakkori & C. Teddlie (Eds.), *The Sage handbook of mixed methods in social & behavioral research* (pp. 69-94). Thousand Oaks, CA: Sage.
- Johnson, D. R., Stodden, R. A., Emanuel, E. J., Luecking, R., & Mack, M. (2002). Current challenges facing secondary education and transition services: What research tells us. *Exceptional Children*, 68, 519-531.
- Kaminsky, L., & Dewey, D. (2001). Siblings relationships of children with autism. *Journal of Autism and Developmental Disorders*, 31, 399-410.
- Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child*, 2(3), 217-250.

- Kapp, S. K., Gillespie-Lynch, K., Sherman, L. E., & Hutman, T. (2013). Deficit, difference, or both? Autism and neurodiversity. *Developmental Psychology*, 49, 59-71.
- Kelloway, E. K. (2015). *Using Mplus for structural equation modeling: A researcher's guide* (2nd ed.). Thousand Oaks, CA: SAGE Publications.
- Khanna, R., Madhavan, S. S., Smith, M. J., Tworek, C., Patrick, J. H., & Becker-Cottrill, B. (2012). Psychometric properties of the Caregiver Strain Questionnaire (CGSQ) among caregivers of children with autism. *Autism*, 16, 179-199.
- Kielhofner, G. (2002). *A model of human occupation: Theory and application*. Lippincott Williams & Wilkins.
- Kim, J. A., Szatmari, P., Bryson, S. E., Streiner, D. L., & Wilson, F. J. (2000). The prevalence of anxiety and mood problems among children with autism and Asperger syndrome. *Autism*, 4(2), 117-132.
- Kim, K.-H., & Turnbull, A. (2004). Transition to adulthood for students with severe intellectual disabilities: Shifting toward person-family interdependent planning. *Research & Practice for Persons with Severe Disabilities*, 29(1), 53-57.
- Kim, Y. S., Leventhal, B. L., Koh, Y. J., Fombonne, E., Laska, E., Lim, E. C.,...Grinker, R. R. (2011). Prevalence of autism spectrum disorders in a total population sample. *American Journal of Psychiatry*, 168, 904-912.
- King, N. & Horrocks, C. (2010). *Interviews in qualitative research*. Thousand Oaks, CA: Sage Publications, Inc.
- Kirby, A. V., Dickie, V. D., & Baranek, G. T. (2014). Sensory experiences of children with autism spectrum disorder: In their own words. *Autism* (Early online publication, 11 pages). doi: 10.1177/1362361314520756
- Kirk, S., Gallagher, J. J., Coleman, M. R., & Anastasiow, N. (2012). Educating exceptional children (13th ed.). Belmont, CA: Wadsworth, Cengage Learning.
- Kline, R. B. (2011). *Principles and practice of structural equation modeling* (3rd ed.). New York, NY: Guilford Press.
- Koro-Ljungberg, M. (2008). A social constructionist framing of the research interview. In J. A. Holstein & J. F. Gubrium (Eds.), *Handbook of constructionist research* (pp. 429-444). New York, NY: The Guilford Press.
- Kraemer, B. R., & Blacher, J. (2001). Transition for young adults with severe mental retardation: School preparation, parent expectations, and family involvement. *Mental Retardation*, 39, 423-435.

- Larson, E. (2006). Caregiving and autism: How does children's propensity for routinization influence participation in family activities? *OTJR: Occupation, Participation, & Health*, 26 (2), 69-79.
- Law, M., Steinwender, S., & Leclair, L. (1998). Occupation, health, and well-being. *Canadian Journal of Occupational Therapy*, 65(2), 81-91.
- Le Couteur, A., Rutter, M., Lord, C., Rios, P., Roberston, S., Holdgrafer, M., & McLennan, J. (1989). Autism diagnostic interview: A standardized investigator-based instrument. *Journal of Autism and Developmental Disorders*, 19, 363-387.
- Levy, A., & Perry, A. (2011). Outcomes in adolescents and adults with autism: A review of the literature. *Research in Autism Spectrum Disorders*, 5(4), 1271-1282.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage.
- Liptak, G. S., Kennedy, J. A., & Dosa, N. P. (2011). Social participation in a nationally representative sample of older youth and young adults with autism. *Journal of Developmental and Behavioral Pediatrics*, 32(4), 277-283.
- Lindstrom, L., Doren, B., Metheny, J., Johnson, P., & Zane, C. (2007). Transition to employment: Role of the family in career development. *Exceptional Children*, 73(3), 348-366.
- Lockyer, L., & Rutter, M. (1969). A five to fifteen-year follow-up study of infantile psychosis. *British Journal of Psychiatry*, 115, 865-882.
- Lounds, J., Seltzer, M. M., Greenberg, J. S., & Shattuck, P. (2007). Transition and change in adolescents and young adults with autism: Longitudinal effects on maternal well-being. *American Journal on Mental Retardation*, 112(4), 401-417.
- Magiati, I., Tay, X. W., & Howlin, P. (2014). Cognitive, language, social, and behavioral outcomes in adults with autism spectrum disorders: A systematic review of longitudinal follow-up studies in adulthood. *Clinical Psychology Review*, 34, 73-86.
- Mandell, D. S., Ittenbach, R. F., Levy, S. E., & Pinto-Martin, J. A. (2007). Disparities in diagnosis received prior to a diagnosis of autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 37(9), 1795-1802.
- Marquenie, K., Rodger, S., Mangohig, K., & Cronin, A. (2011). Dinnertime and bedtime routines and rituals in families with a young child with an autism spectrum disorder. *Australian Occupational Therapy Journal*, 58(3), 145-154. doi: 10.1111/j.1440-1630.2010.00896.x
- Maxcy, S. J. (2003). Pragmatic threads in mixed methods research in social sciences: The search for multiple modes of inquiry and the end of the philosophy of formalism. In A. Tashakkori & C. Teddlie (Eds.), *Handbook of mixed methods in social & behavioral research* (pp. 51-90). Thousand Oaks, CA: Sage.

- Mazurek, M. O. (2013). Lonliness, friendship, and well-being in adults with autism spectrum disorders. *Autism, 18*(3), 223-232.
- Mazurek, M. O., & Kanne, S. M. (2010). Friendship and internalizing symptoms among children and adolescents with ASD. *Journal of Autism and Developmental Disorders, 40*, 1512-1520.
- Mazzotti, V. L., Rowe, D. A., Cameto, R., Test, D. W., & Morningstar, M. E. (2013). Identifying and promoting transition evidence-based practices and predictors of success: A position paper of the Division on Career Development and Transition. *Career Development and Transition for Exceptional Individuals, 36*, 140-151.
- McLoyd, V. C. (1998). Socioeconomic disadvantage and child development. *American Psychologist, 53*(2), 185.
- Migliore, A., Timmons, J., Butterworth, J., & Lugas, J. (2012). Predictors of employment and postsecondary education of youth with autism. *Rehabilitation Counseling Bulletin, 55*(3), 176-184.
- Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis: An expanded sourcebook*. Thousand Oaks, CA: SAGE Publications, Inc.
- Milsom, A., & Glanville, J. L. (2010). Factors mediating the relationship between social skills and academic grades in a sample of students diagnosed with learning disabilities or emotional disturbance. *Remedial and Special Education, 31*(4), 241-251.
- Mishler, E. G. (1986). *Research interviewing: Context and narrative*. Cambridge, MA: Harvard University Press.
- Moher, D., Liberati, A., Tetzlaff J., Altman D. G., & The PRISMA Group (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *PLoS Med 6*(7), 1-6: e1000097.
- Muthén, B. (1984). A general structural equation model with dichotomous, ordered categorical, and continuous latent variable indicators. *Psychometrika, 49*, 115-132.
- Muthén, L. K., & Muthén, B. O. (2012). *Mplus user's guide* (7th ed.). Los Angeles, CA: Muthén & Muthén.
- National Collaborative on Workforce and Disability. (n.d.). *Guideposts for success* (2nd ed.). Retrieved from <http://www.ncwd-youth.info/guideposts>
- Newman, L. (2005). NLTS2 data brief: Family expectations and involvement for youth with disabilities. *A Report from the National Longitudinal Transition Study-2, 4*(2), 1-5.
- Newman, L., Wagner, M., Knokey, A.-M., Marder, C., Nagle, K., Shaver, D.,...SRI International (2011). *The post-high school outcomes of young adults with disabilities up*

- to 8 years after high school: A report from the National Longitudinal Transition Study-2 (NLTS2). NCSE 2011-3005. Menlo Park, CA: SRI International.
- Odom, S. L., Brantlinger, E., Gersten, R., Horner, R. H., Thompson, B., & Harris, K. R. (2005). Research in special education: Scientific methods and evidence-based practices. *Exceptional Children*, 71, 137-148.
- Orsmond, G. I., Krauss, M. W., & Seltzer, M. M. (2004). Peer relationships and social and recreational activities among adolescents and adults with autism. *Journal of Autism and Developmental Disorders*, 34(3), 245-256.
- Orsmond, G. I., Seltzer, M. M., Greenberg, J. S., & Krauss, M. W. (2006). Mother-child relationship quality among adolescents and adults with autism. *American Journal on Mental Retardation*, 111(2), 121-137.
- Orsmond, G. I., Shattuck, P. T., Cooper, B. P., Sterzing, P. R., & Anderson, K. A. (2013). Social participation among young adults with an autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 43, 2710-2719.
- Pergolotti, M. (2013, October). *The influence of perceived occupational possibilities on meaningful activity participation for older adults with cancer*. Paper presented at the annual meeting of the Society for the Study of Occupation, Lexington, KY.
- Repetti, R., Flook, L., & Sperling, J. (2011). Family influences on development across the lifespan. In K. L. Fingerman, C. A. Berg, J. Smith, & T. C. Antonucci (Eds.) *Handbook of life-span development* (pp. 745-775). New York, NY: Springer.
- Reyna, V. F., Chapman, S. B., Dougherty, M. R., & Confrey, J. (2012). Introduction to the adolescent brain: Learning, reasoning, and decision making. In Authors (Eds.) *The adolescent brain: Learning, reasoning, and decision making* (pp. 3-11). Washington, DC: American Psychological Association.
- Robertson, S. M. (2010). Neurodiversity, quality of life, and autistic adults: Shifting research and professional focuses onto real-life challenges. *Disability Studies Quarterly*, 30. Retrieved from <http://www.dsqu-sds.org>
- Rommelse, N. N. J., Franke, B., Geurts, H. M., Hartman, C. A., & Buitelaar, J. K. (2010). Shared heritability of attention-deficit/hyperactivity disorder and autism spectrum disorder. *European Child and Adolescent Psychiatry*, 19, 281-295.
- Rotheram-Fuller, E., Kasari, C., Chamberlain, B., & Locke, J. (2010). Social involvement of children with autism spectrum disorders in elementary school classrooms. *Journal of Child Psychology & Psychiatry*, 51, 1227-1234.
- Roux, A. M., Shattuck, P. T., Cooper, B. P., Anderson, K. A., Wagner, M., & Narendorf, S. C. (2013). Postsecondary employment experiences among young adults with an autism spectrum disorder. *Journal of the American Academy of Child and Adolescent Psychiatry*, 52(9), 931-939.

- Rubin, H. J., & Rubin, I. S. (2005). *Qualitative interviewing: The art of hearing data* (2nd ed.). Thousand Oaks, CA: Sage Publications, Inc.
- Rudman, D. L. (2010). Occupational possibilities. *Journal of Occupational Science*, 17, 55-59.
- Rutter, M., Greenfield, D., & Lockyer, L. (1967). A five to fifteen year follow-up of infantile psychosis: II. Social and behavioral outcome. *British Journal of Psychiatry*, 113, 1183-1189.
- Schaaf, R. C., Toth-Cohen, S., Johnson, S. L., Outten, G., & Benevides, T. W. (2011). The everyday routines of families of children with autism: Examining the impact of sensory processing difficulties on the family. *Autism*, 15, 373-389.
- Scholten-Peeters, G. G., Verhagen, A. P., Bekkering, G. E., van de Windt, D. A., Barnsley, L., Oostendorp, R. A., & Hendriks, E. J. (2003). Prognostic factors of whiplash-associated disorders: a systematic review of prospective cohort studies. *Pain*, 104, 303-322.
- Schopler, E., Reichler, R.J., & Renner, B.R. (1988). *The Childhood Autism Rating Scale*. Los Angeles, CA: Western Psychological Services.
- Schreiber, J. B., Nora, A., Stage, F. K., Barlow, E. A., & King, J. (2006). Reporting structural equation modeling and confirmatory factor analysis results: A review. *The Journal of Educational Research*, 99(6), 323-338
- Schwandt, T. A. (2007). *The SAGE dictionary of qualitative inquiry* (3rd ed.). Thousand Oaks, CA: Sage Publications, Inc.
- Seltzer, M. M., Krauss, M. W., Orsmond, G. I., & Vestal, C. (2001). Families of adolescents and adults with autism: Uncharted territory. *International Review of Research in Mental Retardation*, 23, 267-294.
- Seltzer, M. M., Krauss, M. W., Shattuck, P. T., Orsmond, G., Swe, A., & Lord, C. (2003). The symptoms of autism spectrum disorders in adolescence and adulthood. *Journal of Autism and Developmental Disabilities*, 33(6), 565-581.
- Seltzer, M. M., Shattuck, P., Abbeduto, L., & Greenberg, J. S. (2004). Trajectory of development in adolescents and adults with autism. *Mental Retardation and Developmental Disabilities Research Reviews*, 10, 234-247.
- Shank, K. H. (2013). Mixed methods and pragmatism for research on occupation. In M. P. Cutchin & V.A. Dickie (Eds.), *Transactional perspectives on occupation* (pp. 183-195). New York, NY: Springer.
- Shattuck, P. T. (2006). The contribution of diagnostic substitution to the growing administrative prevalence of autism in US special education. *Pediatrics*, 117, 1028-1037.

- Shattuck, P. T., Narendorf, S. C., Cooper, B., Sterzing, P. R., Wagner, M., & Taylor, J. L. (2012). Postsecondary and employment among youth with an autism spectrum disorder. *Pediatrics*, 129, 1042-1049.
- Shattuck, P. T., Orsmond, G. I., Wagner, M., & Cooper, B. J. (2011). Participation in social activities among adolescents with an autism spectrum disorder. *PLoS ONE*, 6(11), 1-9.
- Shattuck, P. T., Seltzer, M. M., Greenberg, J. S., Orsmond, G. I., Bolt, D., Kring, S., ...& Lord, C. (2007). Change in autism symptoms and maladaptive behaviors in adolescents and adults with an autism spectrum disorder. *Journal of Autism and Developmental Disabilities*, 37, 1735-1747.
- Shea, B. J., Grimshaw, J. M., Wells, G. A., Boers, M., Andersson, N., ...Bouter, L. M. (2007). Development of AMSTAR: A measurement tool to assess the methodological quality of systematic reviews. *BioMed Central Medical Research Methodology*, 7(10), doi: 10.1186/1471-2288-7-10
- Shogren, K. A., & Plotner, A. J. (2012). Transition planning for students with intellectual disability, autism, or other developmental disabilities: Data from the National Longitudinal Transitions Study-2. *Intellectual and Developmental Disabilities*, 50(1), 16-30.
- Simonoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T., & Baird, G. (2008). Psychiatric disorders in children with autism spectrum disorders: Prevalence, comorbidity, and associated factors in a population-derived sample. *Journal of the American Academy of Child and Adolescent Psychiatry*, 47, 921-929.
- Smith, L. E., Maenner, M. J., & Seltzer, M. M. (2012). Developmental trajectories in adolescents and adults with autism: The case of daily living skills. *Journal of the American Academy of Child and Adolescent Psychiatry*, 51(6), 622-631.
- Sparrow, S. S., Balla, D. A., & Cicchetti, D. V. (1984). *Vineland Adaptive Behavior Scales*. Circle Pines, MN: AGS.
- Spitzer, S. L. (2003). With and without words: Exploring occupation in relation to young children with autism. *Journal of Occupational Science*, 10(2), 67-79.
- Subotnik, R. F. (2009). Developmental transitions in giftedness and talent: Adolescence into adulthood. In F. D. Horowitz, R. F. Subotnik, & D. J. Matthews (Eds.) *The development of giftedness and talent across the lifespan* (pp. 155-170). Washington, DC: American Psychological Association.
- Tabachnick, B. G., & Fidell, L. S. (2013). *Using multivariate statistics* (6th ed.). New York, NY: Pearson.
- Taylor, J. L. (2009). The transition out of high school and into adulthood for individuals with autism and for their families. In R. M. Hodapp (Ed.), *International review of research in mental retardation* (Vol. 38, pp. 1-32). New York, NY: Elsevier.

- Taylor, J. L., & Mailick, M. R. (2014). A longitudinal examination of 10-year change in vocational and educational activities for adults with autism spectrum disorders. *Developmental Psychology, 50*(3), 699-708.
- Taylor, J. L., & Seltzer, M. M. (2011). Employment and post-secondary educational activities for young adults with autism spectrum disorders during the transition to adulthood. *Journal of Autism and Developmental Disorders, 41*, 566-574.
- Taylor, J. L., & Seltzer, M. M. (2010). Changes in the autism behavioral phenotype during the transition to adulthood. *Journal of Autism and Developmental Disorders, 40*, 1431-1446.
- Test, D. W., Smith, L. E., & Carter, E. W. (2014). Equipping youth with autism spectrum disorders for adulthood: Promoting rigor, relevance, and relationships. *Remedial and Special Education, 35*(2), 80-90.
- Turnbull, H. R., Turnbull, A. P., Wehmeyer, M. L., & Park, J. (2003). A quality of life framework for special education outcomes. *Remedial and Special Education, 24*(2), 67-74.
- United States Census Bureau (2012). *POP1 child population: Number of children (in millions) ages 0–17 in the United States by age, 1950–2012 and projected 2013–2050*. Retrieved from <http://www.childstats.gov/americaschildren/tables/pop1.asp>
- Vessby, K., & Kjellberg, A. (2010). Participation in occupational therapy research: A literature review. *British Journal of Occupational Therapy, 73*(7), 319-326.
- Vivanti, G., & Rogers, S. J. (2011). Action understanding and social learning in autism: A developmental perspective. *Life Span and Disability, 14*(1), 7-29.
- Wigfield, A., & Eccles, J. S. (2000). Expectancy-value theory of achievement motivation. *Contemporary Educational Psychology, 25*, 68-81.
- Wigfield, A., & Eccles, J. S. (2002). The development of competence beliefs, expectancies for success, and achievement values from childhood through adolescence. In Authors (Eds.), *Development of achievement motivation* (pp. 91-120). New York, NY: Academic Press.
- Wilcock, A. (1999). Reflections on doing, being and becoming. *Australian Occupational Therapy Journal, 46*, 1-11.
- Williams, E., Reddy, V., & Costall, A. (2001). Taking a closer look at functional play in children with autism. *Journal of Autism and Developmental Disorders, 31*(1), 67-77.
- World Health Organization (WHO) (2001). *The International Classification of Functioning, Disability and Health (ICF)*. Geneva, Switzerland: Author.
- Yerxa, E.J. (1993). Occupational science: A new source of power for participants in occupational therapy. *Occupational Science: Australia, 1*(1), 3-9.

- Yerxa, E., Clark, F., Frank, G., Jackson, J., Parham, D., Pierce, D.,...Zemke, R. (1990). An introduction to occupational science: A foundation for occupational therapy in the 21st century. In J. A. Johnson & E. J. Yerxa (Eds.), *Occupational science: The foundation for new models of practice* (pp. 1-17). Binghamton, NY: Haworth Press.
- Young, S. S., & Karr, A. (2011, September). Deming, data and observational studies: A process out of control and needing fixing. *Significance*, 116-120.
- Zwaigenbaum, L., Bryson, S., Rogers, T., Roberts, W., Brian, J., & Szatmari, P. (2005). Behavioral manifestations of autism in the first year of life. *International Journal Developmental Neuroscience*, 23, 143–152.